

*For the Center*

# AIDS ISSUES (Part 3)

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## HEARINGS BEFORE THE SUBCOMMITTEE ON HEALTH AND THE ENVIRONMENT OF THE COMMITTEE ON ENERGY AND COMMERCE HOUSE OF REPRESENTATIVES ONE HUNDRED FIRST CONGRESS SECOND SESSION

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FEBRUARY 27, 1990—AIDS EPIDEMIC AND MEDICAID (H.R. 4080)  
APRIL 19, 1990—FINANCING AIDS EARLY INTERVENTION AND  
TREATMENT SERVICES (H.R. 4470)

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## AIDS ISSUES

### AIDS Epidemic and Medicaid

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TUESDAY, FEBRUARY 27, 1990

HOUSE OF REPRESENTATIVES,  
COMMITTEE ON ENERGY AND COMMERCE,  
SUBCOMMITTEE ON HEALTH AND THE ENVIRONMENT,  
*Washington, DC.*

The subcommittee met, pursuant to notice, at 9:55 a.m., in room 2123, Rayburn House Office Building, Hon. Henry A. Waxman (chairman) presiding.

Mr. WAXMAN. The meeting of the subcommittee will please come to order.

With the President's budget this year, OMB Director Darman included a description of what he called "unfunded liabilities and contingent risks." He used those phrases to describe problems that don't appear on the balance sheet today. Some are real debts that the Federal Government will certainly have to pay, others are potential debts that we should be prepared for.

He forgot one—AIDS. If there ever was an unfunded liability it is this epidemic. Because of years of misplaced moralizing about sex and drugs, the government has missed its opportunity to slow the spread of the virus, and now the weight of the inevitable case-load is coming crashing down on our hospitals and our public financing programs.

If there ever was a contingent risk it is the gamble of how many of the estimated 1 million infected Americans will require hospitalization this year or next. Although drugs to prevent AIDS illnesses are available, the administration has made no plans to provide them to the poor. If a deliberate decision is made not to pay for such drugs, we must prepare now for the unavoidable costs of caring for those people who will become ill.

The sins of the Reagan prevention policy are now visited on the Bush payment plans. Having missed the opportunity to get the ounce of prevention, we now have to pay for the pounds and pounds of cure. Unfunded liability and contingent risks are fancy phrases for a simple truth about AIDS—costs have to be paid. Tens of thousands of Americans have become ill. Hundreds of thousands of Americans are going to become ill soon. Unless we are prepared for the streets of New York to look like the streets of Calcutta, we must get ready to provide hospital, nursing home, home health, and Hospice care for these people. And when we do, costs have to be paid.

The President's budget is constructed as if these costs won't happen, as if the epidemic is over already. Many people are assuming that the worst is over. It's not, the worst is yet to come.

There have been 120,000 cases of AIDS in the United States in the last 8 years and the health care system in urban areas has been stretched to the breaking point. The Public Health Service estimates that there are 1 million infected Americans and that more than half of them have severely compromised immune systems already.

Inner city hospitals are overflowing now. Without some help they will be overwhelmed. Public hospitals are on the edge now. Without some help they will be bankrupted.

AIDS is creating a crisis in access to health care, in financing health care, and in delivering health care. None of these problems is now. All of them are, however, made much worse with AIDS. And these problems are much more immediate and unforgiving with the tidal wave of patients that now need and will continue to call up hospitals and community providers for help.

Medicaid has become a principal source of financing for this help. The Health Care Financing Administration estimates that 40 percent of all AIDS patients at some point become Medicaid beneficiaries. This comes about for a variety of reasons: most common is that people with AIDS often lose their jobs and thus their insurance, and quickly become poor as they pay their health bills.

In addition, the number of women and children with AIDS is growing and the disease is increasingly concentrated among many people who are the poorest of the poor even before they become sick.

Along with almost four dozen of my colleagues, I have proposed legislation to begin to make Medicaid respond more effectively to this epidemic. We hope to deal with our basic problem of getting early intervention drug services to poor patients while such services are still useful.

We hope to assist those hospitals that are struggling with an overwhelming caseload of AIDS patients who depend on Medicaid. We hope to begin using Medicaid dollars to slow the shift of private insurance responsibilities onto public programs and we hope to provide good home care for children with AIDS.

Clearly these proposals are not a panacea for the health care delivery problems that the epidemic poses. Clearly, we need to do more for long-term care for improvement of primary care for psychosocial services and for home and community base services for adults.

This is a starting point. If we can begin by making these changes to the Medicaid system, it will prolong lives, save dollars, keep financially strapped hospitals afloat, and improve care for people with AIDS and all Americans.

If we do not, our whole public health care system may be flooded with sickness, death, and bad debt, and the communities it serves will be devastated.

We must make the start and get ready to pay the costs of AIDS.

[Testimony resumes on p. 16.]

[The text of H.R. 4080 follows:]

101ST CONGRESS  
2D SESSION

# H. R. 4080

To amend title XIX of the Social Security Act to give States the option of providing for coverage for certain HIV-related services for certain individuals who have been diagnosed as being HIV-positive, and for other purposes.

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## IN THE HOUSE OF REPRESENTATIVES

FEBRUARY 22, 1990

Mr. WAXMAN (for himself, Mr. SCHEUER, Mr. WALGREN, Mr. WYDEN, Mr. SIKORSKI, Mr. BATES, Mrs. COLLINS, Mr. RICHARDSON, Mr. TOWNS, Mr. MARKEY, Mr. BRYANT, Mr. PANETTA, Mrs. BOXER, Mr. KILDEE, Mr. BEILSON, Mr. DWYER of New Jersey, Mr. BERMAN, Mr. ACKERMAN, Mrs. BYRON, Mr. CROCKETT, Mr. DE LUGO, Mr. DIXON, Mr. DYMALLY, Mr. EDWARDS of California, Mr. FAUNTROY, Mr. FOGLIETTA, Mr. FRANK, Mr. FROST, Mr. FUSTER, Mr. GILMAN, Mr. GREEN, Mr. HAWKINS, Mr. JOHNSTON of Florida, Mr. KASTENMEIER, Mr. LEVINE of California, Mr. McDERMOTT, Mr. MILLER of California, Mr. PAYNE of New Jersey, Ms. PELOSI, Mr. RANGEL, Mr. ROYBAL, Ms. SCHNEIDER, Mr. STUDDS, Mr. WEISS, and Mr. WHEAT) introduced the following bill; which was referred to the Committee on Energy and Commerce

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## A BILL

To amend title XIX of the Social Security Act to give States the option of providing for coverage for certain HIV-related services for certain individuals who have been diagnosed as being HIV-positive, and for other purposes.

1       *Be it enacted by the Senate and House of Representa-*  
2       *tives of the United States of America in Congress assembled,*

1 SECTION 1. SHORT TITLE.

2 This Act may be cited as the “Medicaid AIDS and HIV  
3 Amendments of 1990”.

4 SEC. 2. OPTIONAL MEDICAID COVERAGE OF HIV-RELATED  
5 SERVICES FOR CERTAIN HIV-POSITIVE INDIVIDUALS.  
6

7 (a) COVERAGE AS OPTIONAL, CATEGORICALLY NEEDY  
8 GROUP.—Section 1902(a)(10)(A)(ii) of the Social Security  
9 Act (42 U.S.C. 1396a(a)(10)(A)(ii)) is amended—

10 (1) by striking “or” at the end of subclause (X),

11 (2) by adding “or” at the end of subclause (XI),

12 and

13 (3) by adding at the end the following new sub-  
14 clause:

15 “(XII) who are described in sub-  
16 section (s)(1) (relating to certain HIV-  
17 positive individuals);”.

18 (b) GROUP AND BENEFIT DESCRIBED.—Section 1902  
19 of such Act is amended by adding at the end the following  
20 new subsection:

21 “(s)(1) Individuals described in this paragraph are indi-  
22 viduals not described in subsection (a)(10)(A)(i)—

23 “(A) who have tested positively to be infected  
24 with the HIV virus and to have (as measured through  
25 an appropriate indicator, such as CD4–T4 cell concen-  
26 tration in the blood) an abnormally low immune func-



tion for which medical intervention is indicated to prevent decline in such function or to prevent opportunistic diseases related to AIDS (without regard to whether or not the individuals display symptoms of AIDS or opportunistic diseases related to AIDS);

“(B) whose income (as determined under the State plan under this title with respect to disabled individuals) does not exceed the maximum amount of income a disabled individual described in subsection (a)(10)(A)(i) may have and obtain medical assistance under the plan; and

“(C) whose resources (as determined under the State plan under this title with respect to disabled individuals) does not exceed the maximum amount of resources a disabled individual described in subsection (a)(10)(A)(i) may have and obtain medical assistance under the plan.

“(2) For purposes of subsection (a)(10), the term ‘HIV-related services’ means each of the following services—

“(A) prescribed drugs,

“(B) physicians’ services and services described in section 1905(a)(2),

“(C) laboratory and X-ray services,

“(D) clinic services, and



1           “(E) case management services (as defined in sec-  
2           tion 1915(g)(2)),  
3 relating to treatment of infection with the HIV virus or treat-  
4 ment for (or prevention of) opportunistic diseases relating to  
5 AIDS.

6           “(3) In this subsection:

7           “(A) The term ‘AIDS’ means acquired immune  
8           deficiency syndrome.

9           “(B) The term ‘HIV virus’ means the etiologic  
10          agent for AIDS.”.

11          (c) LIMITATION ON BENEFITS.—Section 1902(a)(10) of  
12 such Act is amended, in the matter following subparagraph  
13 (E)—

14           (1) by striking “and” before “(X)”, and

15           (2) by inserting before the semicolon at the end  
16 the following: “, and (XI) the medical assistance made  
17 available to an individual described in subsection (s)(1)  
18 who is eligible for medical assistance only because of  
19 subparagraph (A)(ii)(XI) shall be limited to medical as-  
20 sistance for HIV-related services (described in subsec-  
21 tion (s)(2))”.

22          (d) CONFORMING EXPANSION OF CASE MANAGEMENT  
23 SERVICES OPTION.—Section 1915(g)(1) of such Act (42  
24 U.S.C. 1396n(g)(1)) is amended by inserting “or to individ-

1 uals described in section 1902(s)(1)(A)” after “or with  
2 either,”.

3 (e) CONFORMING AMENDMENT.—Section 1905(a) of  
4 such Act (42 U.S.C. 1396d(a)) is amended—

5 (1) by striking “or” at the end of clause (viii),

6 (2) by adding “or” at the end of clause (ix), and

7 (3) by inserting after clause (ix) the following new  
8 clause:

9 “(x) individuals described in section 1902(s)(1),”.

10 (f) EFFECTIVE DATE.—The amendments made by this  
11 section shall apply to medical assistance furnished on or after  
12 January 1, 1991.

13 SEC. 3. OPTIONAL STATE COVERAGE OF HOME OR COMMU-  
14 NITY-BASED SERVICES TO CERTAIN CHILDREN  
15 WITH AIDS.

16 (a) STATE OPTION PROVIDED.—Section 1905(a) of the  
17 Social Security Act (42 U.S.C. 1396d(a)), as amended by  
18 section 6405 of the Omnibus Budget Reconciliation Act of  
19 1989, is amended—

20 (1) in paragraph (21), by striking “and” at the  
21 end,

22 (2) by redesignating paragraph (22) as paragraph  
23 (23), and

24 (3) by inserting after paragraph (21) the following  
25 new paragraph:

1           “(22) home or community-based services (as de-  
2       scribed in section 1915(c)(1)) for children who—

3           “(A) have not attained the age of 18 years,  
4       and

5           “(B) have been diagnosed as having acquired  
6       immune deficiency syndrome (AIDS);”.

7       (b) **OPTIONAL ELIGIBILITY FOR CERTAIN CHIL-**  
8 **DREN.**—Section 1902(a)(10)(A)(ii) of such Act (42 U.S.C.  
9 1396(a)(10)(A)(ii)), as amended by section 2 of this Act, is  
10 amended—

11           (1) by striking “or” at the end of subclause (XI),

12           (2) by adding “or” at the end of subclause (XII),

13       and

14           (3) by adding at the end the following new sub-  
15       clause:

16                       “(XIII) who would be eligible  
17                       under the State plan under this title if  
18                       they were in a medical institution, who  
19                       have not attained the age of 18 years,  
20                       and who have been diagnosed as having  
21                       acquired immune deficiency syndrome;”.

22       (c) **CONFORMING AMENDMENTS.**—Section 1902 of  
23 such Act is further amended—

24           (1) in subsection (a)(10)(C)(iv), by striking “(20)”

25       and inserting “(22)”, and

1 (2) in subsection (j), by striking “(21)” and insert-  
2 ing “(23)”.

3 (d) **EFFECTIVE DATE.**—The amendments made by this  
4 section shall apply to services furnished on or after January  
5 1, 1991, without regard to whether or not final regulations to  
6 carry out such amendments have been promulgated by such  
7 date.

8 **SEC. 4. ADJUSTMENT IN PAYMENTS TO HOSPITALS FOR INDIVIDUALS WITH AIDS.**

10 (a) **IN GENERAL.**—Section 1923 of the Social Security  
11 Act (42 U.S.C. 1396r-4) is amended—

12 (1) in subsection (a)(2), by adding at the end the  
13 following new subparagraph:

14 “(C) In order to be considered to have met such  
15 requirement of section 1902(a)(13)(A) as of July 1,  
16 1991, the State must submit to the Secretary by not  
17 later than April 1, 1991, a State plan amendment  
18 that—

19 “(i) specifically defines, for purposes of sub-  
20 section (f), the hospitals to be treated as dispro-  
21 proportionate share hospitals (and includes in such  
22 definition any disproportionate share hospital de-  
23 scribed in subsection (b)(1) which meets the re-  
24 quirement of subsection (d)), and

1           “(ii) provides, effective for inpatient hospital  
2           services provided not later than July 1, 1991, for  
3           an appropriate increase in the amount of payment  
4           for such services provided by such hospitals, con-  
5           sistent with subsection (f).”;

6           (2) in subsection (b)(1), by striking “subsection  
7           (a)(1)” and inserting “subsection (a)”;

8           (3) in subsection (c)(1), by inserting “(other than  
9           paragraph (1)(C) thereof)” after “subsection (a)”;

10          (4) by adding at the end the following new sub-  
11          section:

12          “(f) ADDITIONAL PAYMENT ADJUSTMENT FOR HOSPI-  
13          TALS WITH DISPROPORTIONATE SHARE OF INPATIENTS  
14          WITH AIDS.—

15               “(1) PAYMENT ADJUSTMENT.—In the case of a  
16          hospital described in paragraph (2), in order to be con-  
17          sistent with this subsection, a payment adjustment  
18          must be made in an amount equal to at least 25 per-  
19          cent of the amount otherwise paid under the plan  
20          (taking into account payment adjustments otherwise  
21          made consistent with subsection (c)) to the hospital  
22          with respect to inpatient hospital services provided to  
23          individuals diagnosed with acquired immune deficiency  
24          syndrome (AIDS).



1           “(2) HOSPITALS WITH DISPROPORTIONATE  
2       SHARE OF INPATIENTS WITH AIDS DESCRIBED.—A

3       hospital is described in this paragraph if the hospital—

4           “(A) is treated under the plan as a disproportion-  
5       ate share hospital (or, but for subsection (e), would be  
6       deemed to be a disproportionate share hospital under  
7       subsection (b)),

8           “(B) during the most recent previous calendar  
9       year for which data are available, had a number of ad-  
10      missions as inpatients of individuals who have been di-  
11      agnosed as having acquired immune deficiency syn-  
12      drome (AIDS) (regardless of the reason for admission  
13      or source of payment) which exceeds 250 (or such  
14      lesser number as the State may specify) or which ex-  
15      ceeds 20 percent (or such lesser percentage as the  
16      State may specify) of the total number of admissions  
17      for that year, and

18           “(C) has made a reasonable effort to reduce the  
19      unnecessary admission as inpatients of at least some of  
20      such individuals through one or more arrangements for  
21      care through any one of the following: a provider  
22      (which may be the hospital itself) that receives funds  
23      under section 317(j)(2), 318(c), 329, 330, 340, 509A,  
24      or 1001 of the Public Health Service Act or title V of  
25      this Act or an entity (which may be the hospital itself)

1 that has under any appropriations Act received funds  
2 as a comprehensive hemophilia treatment center or as  
3 an AIDS service demonstration project.”.

4 (b) CLARIFYING AMENDMENT.—Section 1902(h) of  
5 such Act (42 U.S.C. 1396a(h)) is amended by inserting  
6 “(under section 1923 or otherwise)” after “under this title”.

7 (c) EFFECTIVE DATE.—The amendments made by this  
8 section shall take effect on the date of the enactment of this  
9 Act.

10 SEC. 5. PROVIDING FEDERAL MEDICAL ASSISTANCE FOR PAY-  
11 MENTS FOR PREMIUMS FOR “COBRA” CONTINU-  
12 ATION COVERAGE FOR HIV-POSITIVE INDIVID-  
13 UALS.

14 (a) OPTIONAL PAYMENT OF COBRA PREMIUMS FOR  
15 QUALIFIED COBRA CONTINUATION BENEFICIARIES.—  
16 Section 1902 of the Social Security Act (42 U.S.C. 1396a) is  
17 amended—

18 (1) in subsection (a)(10)—

19 (A) by striking “and” at the end of subpara-  
20 graph (D),

21 (B) by adding “and” at the end of subpara-  
22 graph (E),

23 (C) by inserting after subparagraph (E) the  
24 following new subparagraph:

1           “(F) at the option of a State, for making  
2           medical assistance available for COBRA premi-  
3           ums (as defined in subsection (t)(2)) for qualified  
4           COBRA continuation beneficiaries described in  
5           section 1902(t)(1);”, and

6           (D) in the matter following subparagraph (E),  
7           as amended by section 2(c) of this Act, by striking  
8           “and” before “(XI)” and by inserting before the  
9           semicolon at the end the following: “, and (XII)  
10          the medical assistance made available to an indi-  
11          vidual described in subsection (t)(1) who is eligible  
12          for medical assistance only because of subpara-  
13          graph (F) shall be limited to medical assistance for  
14          COBRA continuation premiums (as defined in  
15          subsection (t)(2))”; and

16          (2) by adding after subsection (s), as added by sec-  
17          tion 2(b), the following new subsection:

18          “(t)(1) Individuals described in this paragraph are indi-  
19          viduals—

20               “(A) who have tested positively to be infected  
21               with the HIV virus (as defined in subsection (s)(3)(B)),

22               “(B) who are entitled to elect COBRA continu-  
23               ation coverage (as defined in paragraph (3)),

24               “(C) whose income (as determined under section  
25               1612 for purposes of the supplemental security income

1 program) does not exceed 100 percent of the official  
2 poverty line (as defined by the Office of Management  
3 and Budget, and revised annually in accordance with  
4 section 673(2) of the Omnibus Budget Reconciliation  
5 Act of 1981) applicable to a family of the size in-  
6 volved, and

7 “(D) whose resources (as determined under sec-  
8 tion 1613 for purposes of the supplemental security  
9 income program) do not exceed twice the maximum  
10 amount of resources that an individual may have and  
11 obtain benefits under that program.

12 “(2) For purposes of subsection (a)(10)(F), the term  
13 ‘COBRA premiums’ means the applicable premium imposed  
14 with respect to COBRA continuation coverage.

15 “(3) In this subsection, the term ‘COBRA continuation  
16 coverage’ means coverage under a group health plan provid-  
17 ed pursuant to title XXII of the Public Health Service Act,  
18 section 4980B of the Internal Revenue Code of 1986, or title  
19 VI of the Employee Retirement Income Security Act of  
20 1974.

21 “(4) Notwithstanding subsection (a)(17), for individuals  
22 described in paragraph (1) who are covered under the State  
23 plan by virtue of subsection (a)(10)(A)(ii)(XI)—

24 “(A) the income standard to be applied is the  
25 income standard described in paragraph (1)(C), and

1           “(B) except as provided in section  
2       1612(b)(4)(B)(ii), costs incurred for medical care or for  
3       any other type of remedial care shall not be taken into  
4       account in determining income.

5 Any different treatment provided under this paragraph for  
6 such individuals shall not, because of subsection (a)(17), re-  
7 quire or permit such treatment for other individuals.”.

8       (b) CONFORMING AMENDMENT.—Clause (x) of section  
9 1905(a) of such Act (42 U.S.C. 1396d(a)), as inserted by sec-  
10 tion 2(d) of this Act, is amended by inserting “or section  
11 1902(t)(1)” after “1902(a)(1)”.

12       (c) EFFECTIVE DATE.—The amendments made by this  
13 section shall apply to medical assistance furnished on or after  
14 January 1, 1991.



Mr. WAXMAN. Before calling on our witnesses, I want to recognize members of the subcommittee for opening statements, and recognize Mr. Dannemeyer first.

Mr. DANNEMEYER. Thank you, Mr. Waxman.

Mr. Chairman, I'd like to thank you for holding this hearing. I look forward to the testimony of our distinguished former Surgeon General, Dr. Koop.

I also find it very interesting by way of contrast what we are about this morning. This legislative hearing is for the purpose of establishing legislative need, or awareness, with a necessity of Federal tax dollars to provide drugs to keep people alive. That is a worthy purpose of this hearing.

It really says we have a major Federal problem on our hands that has to be addressed by all Americans—something that is beyond the ability of the States of the Union, individually or collectively, through their actions and public health departments to resolve.

Yet at the same time, what do we find the current policy of the U.S. Government to be? I am speaking now specifically about the U.S. Public Health Service, currently administered by Dr. Mason, Assistant Director of Health, and Dr. Sullivan, head of HHS. Their policy, so far as I have been able to determine, is the same as advocated by Dr. Koop. We support reportability and contact tracing for HIV carriers, but this is a decision that should be left solely to the exclusive jurisdiction of the States of the Union—contrast what we're saying.

In terms of enforcing the public health laws of America, we will leave the decision to the States. In terms of dividing the money to deal with the tragic victims of this disease, we are going to dip into the Federal Treasury. I find that inconsistent.

I think the time is long past when we should recognize that this Nation is facing an epidemic of major proportions; when we talk about 120,000 Americans who are afflicted, over half of whom have died—this country has lost to this disease than we lost in the entire Vietnam War, and we are still attempting to live the fiction that the Federal response to this epidemic can be pursued and achieved by permitting State public health departments to decide for themselves whether or not they are going to follow the routine way that historically our society has dealt to control communicable disease, reportability for those who have it, and contact tracing. That's nonsense. It's got to stop.

Fortunately, the American Medical Association last December in Hawaii, has finally come around to where they should have been 5 years ago—at least 5 years ago. They said by resolution, this is the official voice of organized medicine speaking. Every State in the Union should have in place on its books a law for reportability of HIV carriers and contact tracing.

What do we find with the two States in the Union? In fact, what do we find with 11 States in America with 78 percent of the cases? They do not have this current process in effect. My State of California, with about 20 percent of the cases; and New York State, with the largest number of cases in the Union, does not mandate that HIV carriers be reported to public health and the blood contact tracing. It's a tragedy.

I've introduced H.R. 3102 last August that measure as a cornerstone of which is reportability for HIV carriers. It's being endorsed by the voices of organized medicine, the State public health authorities. In New York, Massachusetts, Maine, South Dakota, Arkansas, by the president of the Missouri State Society, and a host of medical specialty organizations in America.

I hope, Mr. Chairman, that at sometime in this process a legislative vehicle will be coming along whereby I'll have an opportunity of attaching that bill and be able to have you rule or the House Clerk rule that my bill would pass the test of germaneness because I happen to believe that the time is long past when this Nation should have a force, a rule requiring HIV carriers to be reported to public health and to do the contact tracing.

One final point and I thank you for the indulgence.

For this Nation to attempt to suggest that we can have an intelligent policy for dealing with the AIDS epidemic by continuing its current policy of letting State public health authorities determine whether they're going to mandate the reportability of HIV carriers is kind of like attempting to have run World War II by letting the Governors of the States decide whether or not they are going to send the citizens of their States to defend the Federal Government.

I thank you for your time, Mr. Chairman.

[Mr. Dannemeyer's opening statement follows:]

## OPENING STATEMENT OF HON. WILLIAM E. DANNEMEYER

Last month, the media reported with great fanfare the news that the Centers for Disease Control in Atlanta had revised its official estimate of the number of HIV infected Americans downward by about 15%. CDC now estimates that the total number of cases of full-blown AIDS in 1990 will be between 53,000 and 57,000, instead of the previous projection of 65,000 cases.

These reports have caused some to breath a sigh of relief and conclude that the worst of the epidemic is behind us, that we can laugh about some of the projections of the total number of HIV infected individuals made in the mid 1980s, and that we can devote our time and energy to other issues. It is my assessment that the epidemic is still very much with us, and that CDC's downward revision was ill advised.

First, it now seems that as many as twelve years may elapse before infected individuals manifest the first clinical signs of AIDS, rather than previous estimates of two to six years. Second, AZT and other AIDS drugs

have delayed the onset of the symptoms associated with AIDS. Both of these developments have resulted in the reporting of fewer cases of full-blown AIDS because a larger percentage of the HIV infected population is now asymptomatic than previously believed. A third factor, not to be ignored, is the vast amount of underreporting by physicians with large patient populations of HIV infected persons who do not require inpatient hospital care. As long as patients can be treated on an outpatient basis, many physicians choose not to report and, as a result, the total number of infected appears artificially low to the CDC and others attempting to calculate the size of the epidemic.

I would like to request that an article from the January 30, 1990 issue of the Village Voice describing the full extent of this underreporting be entered in the record at this point.

The witnesses here today have a slightly different story to tell. Their side of the story of this horrible epidemic is reflected in the CDC statistics which show that in the first six weeks of 1990 there were 5,418 cases of full-blown AIDS reported nationwide, a 71% increase over the same six week period last year. For our nation's beleaguered hospitals, the epidemic is growing more, not less, severe.

The chairman of the subcommittee, Mr. Waxman, has introduced H.R. 4080, which attempts to bring federal and state Medicaid funds to low-income HIV infected individuals. I commend him for his effort to provide relief for

the growing number of HIV infected in our inner cities - intravenous drug users, their unsuspecting sexual partners, and, most tragically, their children.

But, H.R. 4080 may prove to be an expensive undertaking, and one which may establish some unsettling precedents for the overall Medicaid program. Nevertheless, it is essential that we examine the problem and ascertain what assistance is feasible, given the overall budgetary constraints we face. We must pay attention, too, to the resolution endorsed last year by 49 governors that calls for a two year freeze on new expansions of the Medicaid program.

I hope that it is possible to demonstrate that these changes to the Medicaid program will result in real savings to the program. After all, it is essential that we find a way to deliver life-prolonging drugs such as AZT to as many HIV-infected persons as possible. It is also crucial that individuals receive the benefits of these drugs as early as possible, especially during their asymptomatic period. Doing this, of course, requires that infected individuals learn their HIV status before they develop clinical AIDS.

I look forward to the testimony from today's witnesses.



# Counting Down

Many AIDS Cases Go Unreported Due to Outpatient Care. Does Planning for the Epidemic Fall Short?

BY PEGGIE EVANS

Is the AIDS epidemic tapering off or are we just not counting properly? That debate heated up again with the report earlier this month of a preliminary study by the Centers for Disease Control cutting projections of new AIDS cases by about 15 percent. The new estimate—roughly 200,000 new cases through 1992—still represents a health crisis of mammoth proportions. Yet the reduced count reinforces perceptions that the disease is coming under control and steer funding away from health care, research, and prevention.

Behind the cut in expected AIDS cases is an even more drastic reduction in estimates of the number of people infected with HIV. Until now, the CDC has presumed that as many as one million to 1.5 million Americans had been infected by 1985, based on small studies of risk groups. But in the new report infection rates are measured by extrapolating from actual cases reported through 1989 and, as a result, the number believed to be infected has been cut in half. This reduction in turn has led epidemiologists to trim the projections for future cases.

Despite the somewhat circular nature of this approach, no one disputes that indeed fewer AIDS cases were reported among gay white men through '89 than originally expected. The dispute is over why. Some experts believe that changes in sexual behavior by gay men limiting the spread of the virus is the primary reason. Others propose that the epidemic has been somewhat self-limiting and that those most susceptible were infected early on. Still others argue that early use of treatment has delayed the onset of symptoms and thus reduced the numbers qualifying for an AIDS diagnosis. If this last camp is correct, then perhaps the epidemic has not been curbed, but merely postponed—unless better treatments come along. It's assumed most of these still relatively healthy infected people will develop the disease within a few years.

On the other side are those who maintain that our methods of measuring the epidemic are insufficient. AIDS advocates staged a demonstration at CDC headquarters in Atlanta on January 9 to argue that some people ill with HIV-related conditions are not being counted because the definition of AIDS is too narrow. They cite several illnesses widely seen among IV users and women—including a form of TB and several gonococcal and bacterial infections—that don't qualify a patient for an AIDS diagnosis but that may be life-threatening. A 1988 New York City health department study suggests that the local caseload among IV users would be 34 per cent higher if a wider range of illnesses were included

in the definition. Yet this battle over the definition doesn't explain why the caseload has fallen short of original predictions, particularly among gay white men. It may be that there are fewer cases. But there also is evidence that growing numbers of people diagnosed are not being reported to the CDC. This is due to a phenomenon that's scarcely been talked about in the press: more and more AIDS patients—particu-

years after diagnosis. Even PLIV still the leading cause of death among people with AIDS, is frequently treated at home by many doctors.

Outpatient care has become more popular for other reasons: it's less costly and less emotionally disruptive to be treated at home. Meanwhile, the rise of the home health care industry has increased alternatives to hospital care. There is little precise data on how widespread outpatient care has become, but—except among indigent patients, who are usually hospitalized at the time of diagnosis—most experts agree it is a growing trend. One of the few pieces of hard data has come from Washington state, where the percentage of reported cases diagnosed as outpatients rose from 6 per cent in 1982 to about 27 per cent in 1989. In interviews, many private doctors in New York, Los Angeles, San Francisco, Houston, and Dallas say that 50 per

cent of more of their full-blown AIDS cases are treated as outpatients for six months to two years or longer after diagnosis.

"You can probably take care of about 65 per cent of initial complications as an outpatient," says Douglas Dietsch of New York University Medical Center. As a result, Dietsch believes, "there probably is significant underreporting." Most private physicians interviewed for this article agree. Many say their outpatients are only reported when they require hospitalization. New York doctor Kenneth Unger says out of his 100 CDC-defined AIDS patients, 80 have never been hospitalized and never been reported. Howard Grossman, another New York physician, says he diagnoses 60 to 75 per cent of his cases as outpatients and many go unreported. Dr. Michael Roth of Santa Monica diagnoses 60 per cent as outpatients and doesn't report. Richard Conklin, a Houston doctor, diagnoses 70 per cent as

outpatients and doesn't report. AIDS registries make it clear that it's hospitals and not doctors who do the reporting. In many major cities nationwide, less than 10 per cent of recorded cases are reported to health departments by private physicians. In New York City, the department of health estimates that doctors register less than 15 per cent of total reported cases. "Our private physicians do not report," says Pauline Thomas, director of AIDS surveillance for the DOH. She considers underreporting due to outpatient care, along with declining infection rates, early use of treatments to delay AIDS, and a speculated outmigration of gay men to be the reasons for the leveling of reported cases among white gays in the city.

Though health officials depend on hospitals to report, many private hospitals also say they don't register patients who use their facilities for lab tests

lestwise that removed a possible collector for the condition. One theory credits the declining use of "paper" labs. But it also may be simply that patients with KS are most often diagnosed as outpatients. NYU's dermatopathology laboratory, perhaps the city's largest facility for diagnosing KS and other such labs across the country, says they leave reporting to private doctors if AIDS is the cause. One San Francisco study found that outpatient care does not account for the decline of KS in that city, though the researchers also concluded that the reason for the decline remains unknown.

George Groopman of Harvard Medical School and other physicians with large AIDS caseloads maintain that the condition is no less prevalent and believe outpatient care may be behind the statistical decline.

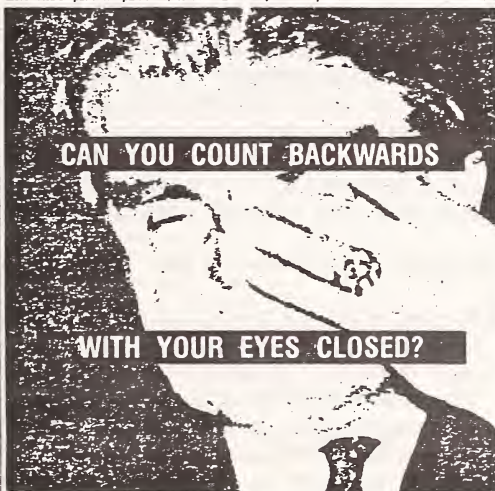
Why are some doctors not reporting full-blown AIDS cases treated as outpatients even though it's required by law? One obvious reason is concern about patients' privacy. As this story went to press the scope of this concern became clear with the swelling controversy over whether New York City's new health commissioner, Norman Myers, might institute reporting of all infected people by name, even those who don't qualify for an AIDS diagnosis. Most AIDS activists, however, viewed for this article felt that mandatory reporting of infected people by name would provide the best tracking of the epidemic—but only in an ideal world. In the real world, they acknowledge that fears over discrimination and the possibility of quarantine drive people away from the health care system. Arguably, the best surveillance requires a combination of strong antidiscrimination protections and a system of anonymously reporting infected people by coded numbers.

Heads of confidentiality, a more common reason doctors cite for not reporting is that, on top of mountains of paperwork they already must complete, they simply don't have time to fill out the registration forms.

George Lemp, San Francisco's AIDS surveillance chief, recommends that doctors be paid for the time spent on the forms. The CDC's chief of AIDS surveillance, Ruth Berkman, says perhaps the reporting process might be simplified.

Earlier in the epidemic, studies in New York City found that reporting of full-blown AIDS cases was 85 per cent complete. But because of new concerns about underreporting, the CDC is now encouraging states to try to extend surveillance to outpatient settings. The New York City health department will soon release a study on how much outpatient care impacts reporting. San Francisco is planning a similar study.

But for now, planning for the epidemic is based on cases reported so far, and if indeed outpatient care, and the delay in diagnosis due to early use of treatment, are disguising the true extent of the caseload, this planning may fall far short. To take one example, critics say the planning for hospital beds in New York won't meet the needs of patients even under the current priorities. Why? If those projections are too low?



larly private patients, who are mostly white gay men—are diagnosed and treated as outpatients. Doctors are required by law to report all cases, but, according to interviews with 80 physicians with some of the largest AIDS practices in the country and with scores of other health officials over the past year, many AIDS cases among outpatients go unreported, sometimes even after death.

Earlier in the epidemic, most AIDS patients were diagnosed in the hospital and thus epidemiologists considered hospital records a reliable means of tracking the epidemic. But today, with advances in monitoring HIV infection, doctors are able to diagnose AIDS earlier, long before hospitalization is required. At the same time, the use of AZT and treatments to prevent opportunistic infections means AIDS patients remain healthier and can be treated as outpatients for months and even

cent of more of their full-blown AIDS cases are treated as outpatients for six months to two years or longer after diagnosis. "You can probably take care of about 65 per cent of initial complications as an outpatient," says Douglas Dietsch of New York University Medical Center. As a result, Dietsch believes, "there probably is significant underreporting." Most private physicians interviewed for this article agree. Many say their outpatients are only reported when they require hospitalization.

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and other care unless they are formally admitted. Of more than 20 private hospitals and laboratories contacted, including some of the largest AIDS care facilities in the nation, nearly all leave it to the doctor to report

## The Age of AIDS

outpatients. Private outpatient hospital records usually don't record whether a patient is HIV-infected or is immune suppressed for some other reason.

Perhaps the clearest impact of underreporting due to outpatient care can be seen among patients with Kaposi's sarcoma. Reported cases of KS have declined sharply over the past few years. This may represent an actual decline due to changes in

Mr. WAXMAN. Mr. Scheuer.

Mr. SCHEUER. Mr. Chairman, I would like to thank you and congratulate you for holding this hearing on what is one of the most agonizing social public policy questions facing our Nation.

What are we going to do about an illness now that by 1992 or thereabouts, we will have 175,000 victims whose treatment is estimated to cost up to \$13 billion—\$13 billion. Already, as you have suggested, the impact of AIDS has some of our State and city health care systems on the edge of a precipice.

In New York State and in New York City, our health care system, due to a lot of causes but certainly the burden of AIDS being preeminent among them, is on the point of collapse. We are on the point of collapse. Our health care system simply can't take it.

And we have some very ugly implications from the fact that we have limited, and put a ruthless limit on the amount of moneys that we spend on all social policies. Within the health care system AIDS is sopping up too many dollars from preventive health care services, from prenatal and postnatal, and we're in danger of finding AIDS moneys to help make the dying more comfortable from moneys that should be spent at very early stages of life giving that life of that infant and that mother more promise, more hope for the future.

So we are stealing from Peter to pay Paul with in the health care system.

And as health care costs gallop out of sight, increasing annually at least two times the rate of the increase in the Consumer Price Index, health care costs are gobbling up other costs. Health care costs, as they increase, are making it more difficult for us to face our problems of infrastructure in this country; more difficult for us to face our problems of education in this country. The \$13 billion that we're estimated to have to pay for AIDS in 3 or 4 years is almost twice the amount that it would cost us to fully fund a Head Start program for every kid at urgent risk of education failure in this country.

That gives us the most agonizing public policy choices of where to spend our dollars, and it is made more difficult by the fact that we put an arbitrary limit on the dollars that are available for these purposes. They are all worthy purposes—education, infrastructure, health; the 31 million uninsured Americans who have no formal access to health care; as well as the claims of the elderly; as well as the claims of infants and mothers.

I would like to repeat the gist of testimony that Herbert Stein gave the Joint Economic Committee not a few months ago. Herbert Stein, a conservative Republican economist who was chairman of President Nixon's Council of Economic Advisers, and he said in effect: We have a \$5 trillion economy. We can do what we want to do. All we need is the intelligence and the courage to make the choices to do the things that are important out of that \$5 trillion economy. If we want to do it, we can do it.

I say that we have to take care of these AIDS cases. It's a most agonizing, horrifying, heart-rending, prospect that we face. But we can't do it to the detriment of all of these other needs, both within



and without of the health care system that are presently competing for pitifully limited dollars.

We have to liberate ourselves, unleash ourselves, and look to that \$5 trillion economy to do the things that America urgently needs to have done.

Thank you, Mr. Chairman.

Mr. WAXMAN. Thank you, Mr. Scheuer.

[Mr. Scheuer's opening statement follows:]

#### OPENING STATEMENT OF REPRESENTATIVE JAMES H. SCHEUER

Mr. Chairman, acquired immunodeficiency syndrome has become a national crisis. Projections are that by 1992, 365,000 individuals will have been diagnosed with AIDS and 66,000 individuals will have died from the disease. By 1992, more than 172,000 AIDS patients desperately will require medical attention that will cost up to \$13 billion. Where this money will come from is an issue that we must confront now, not in 1992. To ignore the question is foolhardy and shortsighted in the extreme.

Presently there are two principal sources of payment for those afflicted with the disease—private health insurance and Medicaid. But many who contract AIDS soon become disabled and unable to work, and thereafter lose their health care coverage.

The disproportionately large burden that a very few States have had to endure is enormous. If major steps are not taken soon, we may witness the total collapse of America's health care system as we now know it.

The National Health Care Financing Administration estimates that currently 40 percent of the Nation's AIDS patients are enrolled in Medicaid. The few States responsible for the lion's share of AIDS cases are facing an impending crisis.

New York, California, New Jersey, and Texas accounted for 62 percent of the new cases in 1988. Currently, Medicaid law requires States and the Federal Government to share Medicaid expenditures according to a formula based on the States' per capita income. Without additional help for AIDS patients, the medical service systems in these States could face total collapse. States will be forced to take money from needed social services such as prenatal care and other preventative services to pay for treatment of AIDS-related illnesses. This only will make it more difficult to provide desperately needed health care coverage for the poor, unemployed and others without health insurance.

Mr. Chairman, it is urgent that we address this issue today. I am very interested in what the witnesses before us have to say, and I hope they will address what steps we must take now to plan for the future.

Thank you.

Mr. WAXMAN. Mr. Nielson.

Mr. NIELSON. Thank you, Mr. Chairman.

I have no formal statement today.

I do want to commend you for having this hearing and particularly bringing Dr. Koop here, who has been one of the leading voices in this area; one who has recognized it's a public health issue, not primarily a civil rights issue as is being treated by some quarters.

We talk about the fact that people get the AIDS through blood supply and through sharing needles. And those things we're working on right now—the blood supply is being taken care of and we hope we can solve that problem.

We talk about the fact that it's increasing in the heterosexual activity—about an 84 percent increase in the last couple of years.

But all of these obscure the fact that the great majority is in the homosexual community. I think the sooner we recognize that and try to deal with it, I think the better off we will be.

I would like to say that at a meeting in Princeton over the weekend, which is our equivalent of the one the Democrats have in the luxurious hotels in West Virginia, we were greeted by a group of

students from Princeton and they were saying, "AIDS, AIDS, we want more, a real commitment to find a cure." And I think that's true; we do need to find a cure.

We need to have FDA get busy and allow some of those things which I have hope to be used as soon as possible. It's a real problem we have and I hope that we can solve it.

I do commend Mr. Dannemeyer for his H.R. 3102 and also you, Mr. Chairman, for your bill that you have here—I think we need to get on with it. But let's treat it as a lice issue, treat it like with any other very epidemic disease. It does cross State lines; I agree with Mr. Dannemeyer in that count.

Thank you, Mr. Chairman.

Mr. WAXMAN. Thank you, Mr. Nielson.

Dr. Rowland.

Mr. ROWLAND. Thank you, Mr. Chairman.

Yesterday I was in New York City with the National Commission on AIDS for site visits there and learned that AIDS is the third cause of death now behind cancer and heart disease.

The principal focus was on the homeless and their problems with AIDS. One-third of the homeless people in the city are known to be seropositive.

It's very difficult to get these people—the homeless—to come in for testing. Two of the problems: one, confidentiality. They are concerned that if they are tested and found to be seropositive then they will be ostracized from even the poor circumstances that they already have.

The other is intimidation by the system in trying to get Medicaid. Most of these people are eligible for Medicaid. But they tell me that the system is so intimidating that they do not even apply for it.

I had the opportunity to look at some of the efforts that are being made there by groups to deal with the homeless problem and the AIDS issue. I went into flophouses, I went into the subway where these people live, and it's almost unbelievable, the circumstances in which they live. And I asked the person that was showing us around, are you winning this battle? And he said, no, we are losing this battle. We are only fighting a rear guard action.

It concerns me when I read that the number of AIDS cases are leveling off in this country. Mr. Chairman, it is a disease that threatens the very fabric of our medical care delivery system.

We do not have a national policy to deal with AIDS. If we do not develop a national policy to deal with AIDS, I think this threat to our health care delivery system will become a reality.

I want to express to you my appreciation for focusing on this issue here today, and thank Dr. Koop for being here.

Mr. WAXMAN. Thank you very much, Dr. Rowland.

[The prepared statement of Mr. Towns follows:]

#### OPENING STATEMENT OF HON. EDOLPHUS TOWNS

Mr. Chairman, I can think of no health issue of greater importance to our Nation, today, than AIDS. New therapies suggest that early intervention can prolong life. Yet, our hospitals, particularly, our public facilities, are in a crisis situation as a result of the cost of treatment associated with this illness. In fact, the future of many of our Nation's public hospitals, including those in the State of New York, are dependent on how we support the financing of services for AIDS patients. Certainly,



your efforts Mr. Chairman, through H.R. 4080 will go a long way toward addressing these financing problems. I am hopeful that we will move quickly to pass this legislation in the House and to enact this bill this year. I look forward to hearing from our witnesses this morning on how we can better address both the treatment and the financing issues involved with AIDS.

**Mr. WAXMAN.** Dr. Rowland is the doctor on our subcommittee but Dr. Koop is this Nation's doctor because he has drawn attention to the public health concerns that can lead to a healthier America and a better life for all of our people.

As we look today at the Medicaid program, Dr. Koop, you saved more money in Medicaid than Richard Darman and David Stockman and all these others, without cutting services to the poor, because you have highlighted the fact that we need to keep people from getting sick in order to cut back on health care services in a much more intelligent way.

We are delighted to welcome you back to our subcommittee hearing today and since you were one of the leaders in talking about the AIDS epidemic and how to deal with it, we thought it appropriate to have you with us as we look at this problem now in terms of the aspects of giving care to those patients who need the care.

#### **STATEMENT OF C. EVERETT KOOP, FORMER SURGEON GENERAL, PUBLIC HEALTH SERVICE**

**Mr. KOOP.** Thank you, Mr. Chairman.

I do appreciate the opportunity to address the committee on certain aspects of the AIDS epidemic. I am also grateful to you, sir, for your maintaining a forum for continuing discussion of this epidemic.

First, may I remind the committee that there are still several aspects of AIDS that color everything we say and do about the disease and raise barriers in dealing with the epidemic comfortably. AIDS is still somewhat of a mystery to most people; it is fatal, and people get AIDS by doing things that most people do not do and do not approve of.

These factors still keep many from addressing the issues that might contain the epidemic and provide necessary care for those afflicted by the disease. Instead, frequently our attention is turned toward more volatile issues of law, of ethics, of economics, morality, and social cohesion.

The close of 1989 saw 117,000 recorded diagnoses of AIDS, more than half of them dead; 35,000 new cases in 1989, and 40,000 new cases predicted for this year.

The medium has done a credible job of informing the public of a most complicated disease and of keeping the epidemic before them. I have been surprised that the public's attention could be held so long.

Mr. Chairman, since leaving public office I have continued to travel about the country and indeed may, in some circumstances, have better access to parts of the health care system today than I had previously.

I have become convinced that the figures I just quoted for you are underreported. I am also disappointed to sense a kind of complacency about the AIDS epidemic. This, I think, for at least three reasons.



First, there are those who interpret the slightly reduced projections for new cases this year as evidence that the epidemic is over. It is not.

Second, there are others who view the disease as not their problem. After all, aren't most of the new cases turning up in predominantly black and Hispanic intravenous drug abusers, they say? And I'm sure that you've heard that many times.

And, third, there are many misled by inaccurate assessments in books and magazines that are convinced that AIDS is not spread heterosexually. The truth is that it is passed heterosexually, male to female, and female to male, and don't forget their progeny.

My final concerns, Mr. Chairman, have to do with health care for persons with AIDS. When I released the Surgeon General's report on AIDS in October of 1986—a report, incidentally, which is still accurate—I said that the epidemic of AIDS would impact on everyone in America. It already has in many subtle ways, but let me speak about the care of patients.

In New York City it is estimated that a quarter of the hospital beds are now occupied by AIDS patients. And the problem of babies with AIDS is growing by the day. There is ample anecdotal evidence of the anger and the frustration of families who cannot get a hospital bed for a loved one because it is occupied by an AIDS patient.

I think it was before this same committee, Mr. Chairman, that I predicted this situation and urged that it be prevented. Babies born with HIV positive, who eventually develop AIDS, are frequently addicted to the drug their mothers were addicted to at the time of delivery.

In a city I visited just recently, an addicted mother, her baby less than a day old, walked out of the hospital with an intravenous still attached to her arm—either forgetting or not caring that she left her child behind to the abandoned State so many of these unfortunate youngsters inherit.

Mr. Chairman, public health and governmental goals in the epidemic remain the same. Even as the situation worsens, and will continue to do so, we need to keep the infected from infecting others and where possible, we must postpone the onset of opportunistic disease and treat it in settings other than acute care hospitals.

Persons with AIDS need help—they need it physically and financially. Hospitals that have a disproportionate caseload of AIDS need help as well as an alternative to hospital care for AIDS babies, especially those abandoned, must be found.

Mr. Chairman, much of what I have said this morning I have said over and over again for the last 5 years. My concerns expressed this morning have yet to be addressed at a national level. Unless there is a congressional intervention, the situation can only get worse. Indeed, it is of critical importance now in some urban areas.

Mr. Chairman, if the transmission of HIV could be stopped today—and there is no sign of that happening even in the distant future—we would still have the relentless need to care for the more than a million HIV positive patients not yet showing signs of this disease.

Thank you, Mr. Chairman.

Mr. WAXMAN. Thank you very much, Dr. Koop.

As we look at trying to deal with this epidemic it seems to me we have two preventive measures we can take. One, we need to prevent the spread of the virus and; second, for those who have the virus, we can prevent the virus from becoming AIDS itself.

Do you feel that if we allowed and provided for early intervention drugs that people would be encouraged to come in for testing and counseling to deal with their medical infection, their medical problem?

Mr. KOOP. I think that that already has been shown to be the case. When a patient feels that there is sufficient reward for taking the risk of losing their confidentiality and privacy that he has cherished up until that point, he will make the effort to do so. But it is very difficult to encourage someone who only faces the ridicule of society to take that risk if there's no reward.

Mr. WAXMAN. Right now we have people who are afraid to go in for testing and counseling because they fear the breach of confidentiality, they fear the discrimination that may result. And in the past, they fear the fact that there was nothing they could do about the fact they were infected except, perhaps, maybe even face a death sentence as a result of going in for the testing.

Now if someone goes in to be tested, they can get an early intervention drug that will keep them from developing AIDS.

Do you think that has changed in the whole picture in terms of testing and counseling?

Mr. KOOP. I think it has, sir. And I think that in places where it is being effective, already more patients are turning up for counseling. And not only is the early intervention of drugs in reference to the disease itself but also substances like aerosol pentamidine and those who have a falling T-cell count can take that prophylactically and prevent the onset of pneumocystis carinii pneumonia, which is the thing that kills most of them.

Mr. WAXMAN. Does it make any sense for us as a society to put resources in for testing people to see if they are HIV positive and then to put money in to take care of the acute care that's going to be needed for those who have AIDS without providing in addition the money for early intervention drugs to slow the progress of the disease?

Mr. KOOP. I think it's a package. I think if one is going to step into a more active testing and counseling, you have to provide those drugs. But I think that part of that is to provide the drugs eventually in some setting other than the acute care hospital, which is what is causing the crunch in urban areas like New York that Congressman Scheuer just referred to.

Mr. WAXMAN. We are faced with a crazy catch-22 in our Medicaid law. To be eligible for Medicaid, you have to be disabled. And once you're disabled you get your health care bills paid. But if you're poor enough for Medicaid and need the money for early intervention drugs, and you're not disabled because early intervention drugs will keep you from being disabled, you're not eligible to get those drugs paid for.

That seems to me to be a catch-22 that makes no sense, and I urge in our legislation to provide Medicaid payment for those drugs.



I assume you would support that?

Mr. KOOP. I do support that, sir.

Mr. WAXMAN. While there's evidence that the rate of new infections among white gay men in some cities is going down, the new infections among other risk groups, other gay men, drug abusers, women and infants, are all going up.

Why do you think this is so, and what can we do to improve the situation?

Mr. KOOP. I think we're dealing with a problem that education finds very difficult to approach. As I have testified before this committee, my own experience in dealing with intravenous drug abusers is that they lead such fragmented, compartmentalized lives that it is very difficult for them to come into the mainstream of health care to heed the warnings about sharing drug paraphernalia if they're abusing drugs, and to assume the responsibility for the children that are born by the sexual activity of drug abusers.

As you know, the mothers of most babies with AIDS either are themselves drug abusers or they are the sexual partners thereof, which is one further proof that the heterosexual spread of AIDS is not something to be sneezed at.

It is an extraordinarily difficult subject, and I think all that one can do is to keep after it to the best of one's ability and hope that some will listen. Of course, if we could improve the ability to treat those who are addicted to IV heroin, for example, that is one of the best ways to corral a patient and to approach him in reference to the other problem he has, namely, AIDS and the contact tracing thereof.

Mr. WAXMAN. Thank you very much.

Mr. Nielson.

Mr. NIELSON. Dr. Koop, the chairman has raised an interesting point about how to be disabled to get Medicaid. One of the provisions of his bill, H.R. 4080, defines an individual who is asymptomatic, HIV positive, and disabled for purposes of qualifying for Medicaid. These individuals must be distinguished from those suffering from full-blown AIDS, or AIDS related to complex.

Could this set a precedent for establishing Medicaid eligibility based on a specific illness or condition?

Mr. KOOP. I think there's the great risk that it could do that, sir. But on the other hand, I think we're dealing with a very unique situation, and if the patients we're talking about could be kept active and independent, there is a saving of funds from whatever source they come in the long run.

Mr. NIELSON. Now, if HIV-infected people could be made disabled because of their condition, why not apply that to cancer and heart trouble people who may be disabled for all practical purposes and yet not qualify for Medicaid under present laws?

Mr. KOOP. I don't think that with a cancer patient if you approached him or her in the same way we're talking about approaching an AIDS patient that you could indeed postpone the symptoms of the disease that you could keep the patient active longer, that you could keep them independent, and in a sense postpone the final days of this terrible syndrome for a number of years.

Mr. NIELSON. What about diabetes?

Mr. KOOP. Diabetes is almost the same situation, except that we do have something for diabetes until it gets to the point of being brittle and very complicated at the end of the disease to do just that. In a sense, the provision of insulin for a diabetic is doing exactly what this bill proposes that you do for AIDS patients.

Mr. NIELSON. So you feel that classifying those who are asymptomatic of HIV positive as disabled, even though it sets a precedent, it's worth it, and even extends to other illnesses?

Mr. KOOP. I'm not a prophet, sir, but from where I sit it seems to me that that is the reasonable way to go, perhaps the only way to go in this epidemic.

Mr. NIELSON. I thank the chairman.

Mr. WAXMAN. Thank you, Mr. Nielson.

Mr. Scheuer.

Mr. SCHEUER. Thank you, Mr. Chairman.

It's a great pleasure to have you back here, Dr. Koop. Your appearances here are always epic—you always educate and enlighten.

Can you tell us, relative to my remarks about New York, just give us a sort of a mole's eye view, not of the grand panoramic picture of our country, but of the situation in the cities and States that have an overwhelmingly disproportionate burden of AIDS—New York City, New York State, New Jersey, California, Texas?

What is the situation there? How has this epidemic affected the health care systems financially in terms of human resources, plant, equipment?

And what do you see as a logical and rational Federal approach, not only to the problem nationally, but also especially to the cities like New York City, whose health care systems are absolutely, as I understand it—and please correct me if I am wrong—at the point of collapse?

Mr. KOOP. To answer your question properly, sir, would take a monograph, but I'll try to hit the highlights.

In a city like New York, the health care system is affected in innumerable ways. First of all, the caseload of patients who are ambulatory is very high, and when they use emergency rooms of hospitals as their family doctor, which is their custom, they run into the first situation that has changed since this epidemic has been with us.

The people who staff the emergency rooms are understandably concerned that they may indeed themselves catch this disease—not by casual contact but by catching blood in a cut in the hand, and so forth. And as I talk to house officers in some of the hospitals in New York City, they say, we know we are not giving the same quality of care to any patients because we're afraid of all of them. So that's No. 1.

No. 2 is some of those great hospitals in New York, Chicago, San Francisco, that used to attract the very best of our postdoctoral people, both in nursing and in medicine, no longer want to go there. They say, why go to a hospital where 25 percent of the beds are filled with the same diagnosis; we would like to see more variety. And in addition to that, every one of those patients is a potential source of infection to us should there be some kind of a mishap.

The third thing that happens in those hospitals is that the very ones which opened their doors autistically in the beginning to AIDS patients began to suffer in two ways: most AIDS patients are spent down by the time they're admitted and, therefore, they are taking care of patients who either come in impoverished or become that while they are there.

But second, they have difficulty in attracting other patients to the hospital because non-AIDS patients are afraid to go to hospitals where there are 25 percent of the beds occupied with AIDS patients, and they are also afraid that maybe their friends will think that that's why they went to the hospital. So there's a two-pronged problem there.

That situation has changed in the last year—actually since last April—when the beds are now so filled in New York that the problem has become a little bit different. You can find an awful lot by talking to a taxi driver in New York about difficulties he had getting his family to a hospital; and when he inquires why he can't get his mother in to have her gall bladder fixed when he wants to, he's told, well, we have so many AIDS patients that we have a long waiting list. So that is the way the system impacts upon the delivery of health care, but also on the education of young physicians which will be felt not just now but down the road.

Then when you talk about the number of people on the streets that have this disease, there has to be some way that they can be counseled to come to places where they get the kind of care that Mr. Waxman was just talking about. But further than that, when they have AIDS and are terminally ill to have the assurance that they don't have to be turned away from an acute care hospital, which is not where they belong, but that there should be someplace that provides terminal care for AIDS patients which does not have to consist of more than shelter, warmth, blanket, and tender loving care.

Now, you asked what the action should be on the part of the Federal Government in order to address some of these issues—I guess I must have said it from public platforms a hundred times and at committee meetings like this 15 times, it seems to me incredible that the Federal Government has not had a dialogue with States and with certain municipalities to undertake some kind of projection on who is going to pay the cost of this epidemic; what its effect will be on the insurance industry; and how we can better care for terminal patients without producing all the disruption of health care that I just mentioned, and do it in a more efficient and cheaper fashion.

That's why I think it's very important that anything that this committee does to address the subject from a Federal point of view is very important.

Mr. SCHEUER. Doctor, let me just add the followup. You talked about other settings.

Can you tell us something about how those other settings might appear where we could rely perhaps more on paraprofessional health care involving fewer doctors and fewer registered nurses and providing the basic essential services that you said—heat, light power, blankets, and whatnot—in an environment that wasn't billed at a cost of several hundred dollars per square foot like a



hospital? That's an extremely expensive environment to provide rather simple custodial care to make life a little pleasanter, a little less painful, in their terminal months.

What kind of a setting do you visualize?

Mr. KOOP. There are places already available that were built as hospitals and have been closed or abandoned. There are military hospitals that are in mothballs. The difficulty is that none of them exist in the midst of the urban area that you're talking about.

As I have discussed this with the former Commissioner of Health of New York, Dr. Steven Joseph, the question is, how do you provide for people in the City of New York, for example, that you would have to move maybe 40 miles away, what will substitute for the family and friend support that they get that visit them in the hospital?

But I think it would be far cheaper to bus people 40 miles—

Mr. SCHEUER. Send them by Carrie Cadillac.

Mr. KOOP. Pardon?

Mr. SCHEUER. Send them by Carrie Cadillac, for goodness sake.

Mr. KOOP. That's a little expensive; there are cheaper ways.

Mr. SCHEUER. The point is you could afford to do that; the savings would be so vast.

Could much of this care, or most of this care, be provided by paraprofessionals?

Mr. KOOP. In terminal circumstances, yes, sir. You don't need respirators and IV lines and that sort of stuff when the patient is terminal.

And I think that when patients who are terminal are admitted to acute care hospitals, it is very difficult for acute care personnel to look at a patient and say, he's terminal, we're not going to do anything more than he needs right now—they step in with high tech, high cost medicine, and they prolong it until the end.

Mr. WAXMAN. Thank you, Mr. Scheuer, time has expired.

Mr. SCHEUER. Thank you.

Mr. WAXMAN. Mr. Dannemeyer.

Mr. DANNEMEYER. Dr. Koop, welcome.

Mr. KOOP. Thank you.

Mr. DANNEMEYER. The issue, among others, is what the Federal Government's policy is, or should be, and as far as I know you're not currently serving in an official capacity with the Federal Government; that's a correct statement, isn't it?

Mr. KOOP. That is correct, sir.

Mr. DANNEMEYER. Do you believe that I have correctly stated the current policy of the U.S. Government on the issue of reportability, that it's essentially a State option?

Mr. KOOP. You haven't been quite accurate, sir, in that you always associate, when you talk about it, testing and contact tracing. There are many States who require reporting of persons with AIDS either by name or by number, but they don't all have contact tracing.

As you and I have discussed many times before, the problem with this disease is that you don't have very much to offer them in contact tracing, especially when the risk of their loss of privacy and confidentiality is—

Mr. DANNEMEYER. Dr. Koop, the question is, sir, did I correctly state the current posture of the U.S. Government that reportability is a State option?

Mr. KOOP. That is true, but that is not the question you asked.

Mr. DANNEMEYER. My next question, sir, is, do you believe we have a Federal problem on our hands in terms of providing funding for AZT for persons who are HIV carriers?

Mr. KOOP. Absolutely.

Mr. DANNEMEYER. So that's a Federal responsibility, right?

Mr. KOOP. I think it is.

Mr. DANNEMEYER. Do you think we should then say to the States that want this Federal money that as a condition of getting this Federal money they have to put in place the routine steps that have historically been pursued to control a communicable disease, which now has been endorsed by the official voice of organized medicine, the American Medical Association?

Mr. KOOP. No, I don't believe that, sir, because it doesn't work quite that way, Mr. Dannemeyer. The official voice of organized medicine stated it in that direction but they also agree a similar amount of zeal must be exerted to protect the privacy and confidentiality of individuals as is exerted in doing the other things that you suggest.

Mr. DANNEMEYER. Dr. Koop, let me say right now that from the beginning of our involvement in this epidemic and my attempt to move the Nation to treat it as a public health issue and not a civil rights issue—what it currently is doing.

I have said repeatedly that who has what disease in this country is none of my business, it's none of any member of Congress's business, but it is the business of public health authorities to whom reportability of communicable disease has been a historical pursuit in confidence in conducting contact tracing.

Now you said that certain States—the fact of the matter is that 15 States in America currently, according to my latest count, mandate reportability of HIV carriers. Well, they have reportability for HIV carriers—3 of those 15, it's optional, so we have 12 that mandate reportability. But those 15 States contain 8 percent of the cases, and of the 2 States with the biggest share of the cases—New York and California—we are still, as I say, not having in place the routine steps that have historically been pursued to control communicable disease.

Now, I think it's an absurdity, sir, to be honest with you, that we in this Congress would seriously think about pursuing a policy of expending billions of dollars to provide a drug to keep people alive, which I think is a humanitarian duty that we all have in this country, and I want to make that clear. But at the same time say, now, we're not going to require that the States, who are administering these funds, have in place routine steps that have historically been pursued to control communicable disease.

Don't you think there's a conflict there?

Mr. KOOP. I have never taken the position, sir, that the States should not report the existence of HIV positivity to State health departments. I have differed with you on what you do thereafter because I don't share with you the enthusiasm that contact tracing will turn this epidemic around.

Mr. DANNEMEYER. Let me look at it this way—if I may have, Mr. Chairman, additional time—is that don't you believe it's now time in the history of this epidemic for the Federal Government, which essentially defines what a disease is, to change the classification of a disease and fully developed AIDS to an HIV carrier?

Mr. KOOP. I don't think I understand your question.

Mr. DANNEMEYER. The American Academy of Science several years ago recommended that we just change how we categorize or treat this epidemic, instead of waiting until one of us fully develops AIDS to classify that as a case, we would say that the definition of the disease is an HIV carrier.

Mr. KOOP. I don't think that there is any doubt about the fact that that's being done in most places, sir.

Mr. DANNEMEYER. Do you think that's the policy that should be followed by the U.S. Government, that's my question?

Mr. KOOP. If it doesn't have strings attached to it.

Mr. DANNEMEYER. What strings are there?

Mr. KOOP. Well, you've always attached—

Mr. DANNEMEYER. The CDC—wait a minute—the CDC right now has the authority to define a disease, correct?

Mr. KOOP. They have defined it as an infectious disease and one which is sexually transmitted.

Mr. WAXMAN. The gentleman's time has expired. We will have an opportunity of a second round if you so desire.

Dr. Rowland.

Mr. ROWLAND. Thank you, Mr. Chairman.

Dr. Koop, you've already expressed the thought that there are mysteries that surround this disease—what causes it is constantly changing, is almost as though it's a will-o'-the-wisp. There's a prolonged period of time between the infection of an individual and the manifestation of symptoms—years, in fact. I don't know that we've had a disease that I know anything about to deal with just like this. There's so many ethical, moral, and legal implications to this disease, it seems to me that we've never had to deal with before.

An individual who may be infected with this virus may be symptom-free and continue to function in society. It is a disease based on our present knowledge that it is not transmitted by casual contact; it's not really that contagious unless you involved yourself in certain activities.

I agree with the gentleman from California, that we don't have a national policy at this point. It seems to me that we should have some type of policy to address the confidentiality of people who are infected with this virus because there's still a great deal of fear about it and about what it will do.

We talked about contact tracing. Let me ask you this question: Are names important in contact tracing with this disease?

Mr. KOOP. They are important to the people who are asked to counsel the contacts of persons with AIDS, yes; they are not important to other people.

Mr. ROWLAND. That's my question principally, are they important to other people?

It seems to me that if we do contact tracing with names, we are actually going to drive the disease underground to a large extent.



We will not have people coming in to get tested even in spite of the fact that we now know that if we use such drugs as AZT for the seropositive state before the disease develops, it does give some hope. But it seems to me we haven't reached that point yet that the benefits outweigh the loss of confidentiality.

Mr. KOOP. That's what I think most public health officials would agree with you today on that very point.

Mr. ROWLAND. Isn't that what CDC principally believes?

Mr. KOOP. Yes, sir.

Mr. ROWLAND. It's a very difficult disease for us to try to deal with. I think we have to be extremely careful in dealing with it, so that we don't do the opposite of what we intend to do, because I think it's very easy for us to do that.

Let me focus on one other area. We talked about the urban areas, and I mentioned that I was in New York City yesterday and what's going on there. But there is a tremendous increase in HIV in the rural areas.

In fact, in my own State of Georgia, from 1987 to 1989, we saw a 300 percent increase in the center of the State in the rural areas principally related to drug abuse—crack cocaine is into that area now. I just want to focus attention on that to the extent that I don't want the rural areas to be left out in any discussion about the spread of AIDS. I am sure you are aware of this also, that that is really what's taking place.

Mr. KOOP. I try to make the point all the time when I'm speaking about this publicly, sir, that if you take a sigh of relief because you don't live in Chicago, Newark or San Francisco, that those days are numbered, because within this decade the number of rural cases will exceed those that are in the urban areas.

Mr. ROWLAND. And there is a significant increase in heterosexual spread in the rural areas?

Mr. KOOP. Yes, sir.

Mr. ROWLAND. Thank you, Dr. Koop.

Thank you, Mr. Chairman.

Mr. WAXMAN. Thank you, Dr. Rowland.

Do any members wish a second round of questions?

Mr. Dannemeyer.

Mr. DANNEMEYER. To come back to this point, Dr. Koop, about how the U.S. Government defines the disease itself. There are two ways as I see it: One would be we could continue the current policy of defining the disease as fully developed AIDS with immune system deteriorated to the point where opportunistic diseases confront that individual and cause their death; or we could follow the recommendation of the American Academy of Science which says we change the definition of the disease itself to an HIV carrier; do you favor that?

Mr. KOOP. I would favor that, sir. I think that you are talking about now having a Federal policy, I don't think you should focus the necessity for a Federal policy on just this one issue. We don't have a Federal policy on AIDS, period.

We've had the recommendation of the commission that was appointed by the President. I don't know what's happened to all of their recommendations.

We have a current commission that periodically reports rather than waiting until the end of the time. There are ample opportunities for Congress, for the Executive Branch, to get together and establish an AIDS policy in this country, and I think it's almost 10 years overdue.

Mr. DANNEMEYER. Let's come back to the efficacy of contact tracing. The State of Colorado, for instance, in its program of contact tracing has found that 13 percent of those who have been contacted or had sexual contact with an HIV carrier or somebody with AIDS were positive and 87 percent were negative. Those 13 percent who are positive can then be counseled and advised that they are positive themselves.

Don't you think that's a benefit that comes from contact tracing?

Mr. KOOP. I've always said that was the case, sir, and most people who find an individual who was HIV positive do follow that exact train. But it is not mandatory to do so, and to make it mandatory many public health people feel would, as Dr. Rowland has said, drive the very people underground that you are trying to reach and counsel.

Mr. DANNEMEYER. We were at the point today where, for instance, the medical societies of the States of New York, Massachusetts, Maine, South Dakota, Arkansas, and West Virginia disagree with your statement, because those medical societies have all endorsed H.R. 3102, which would require that as a condition of States getting Federal dollars to deal with the epidemic they must put into place certain routine steps to control the epidemic from moving the people that have it to those that don't want to have it—the cornerstone of which is reportability.

So I think that there is a significant voice, and I think New York's position is extremely significant, sir, as we both know. It happens to be the State in the Union with the largest number of AIDS cases—a little over 20 percent. And when the voice of organized medicine in that State endorses the bill that I've talked about, I think it says something to the American public as to the fact that we should move away from treating this as a civil rights issue and not a public health issue, and on this point of contact tracing that you and I, and reportability—you and I have discussed over the years, we've been privileged to discuss the matter.

The American public can't understand something, sir. We in America, through our public health officials, will conduct a policy of mandatory reportability and contact tracing for curable venereal disease—historically we've done that in America, at the State level.

And yet we have set aside that policy, which is designed to prevent the transmissibility of curable venereal disease from the infected to the uninfected in dealing with this noncurable venereal disease called the virus HIV. People can't understand that, Dr. Koop, they are confused—why we would have one policy for reportability, mandatory and contact tracing for a curable venereal disease and yet not have the same policy for a noncurable venereal disease.

Mr. KOOP. I think it's the term "curable" and "noncurable" on which the whole argument hangs. You have yourself talked many times about the comparison of this epidemic with that of syphilis,



and the difference is that we had tests for syphilis for 17 long years before we ever made it mandatory for people to be tested.

Mr. DANNEMEYER. Dr. Koop, you know as well as I do that before we had a cure for syphilis we mandated reportability in this country.

Mr. KOOP. No, sir, we did not.

Mr. DANNEMEYER. You and I are reading the same history books and coming here for conclusion.

Mr. KOOP. The first mandated law was put on the books and only then because we had a cure for syphilis. That is public health history, sir.

Mr. DANNEMEYER. You are reading different history books than I am, Dr. Koop. I think Dr. Perrin, in his book, "Shadow on the Land," published, I think, in 1933, made very clear what steps this Nation should pursue at that time. And the strange thing—not strange, but the interesting paradox about it is the steps that this member on this subcommittee has been attempting to get this Nation to implement are nothing more than what Dr. Perrin, the former Surgeon General of the United States, talked about—the steps that we should take to control syphilis, and when it was an epidemic in the country, that we should be pursuing today and putting in place to control this new, noncurable venereal disease.

Thank you for your time.

Mr. WAXMAN. The Chair recognizes himself for a second round.

Dr. Koop, this hearing was called for the purpose of talking about the health care treatment for people with AIDS, care of intervention for those who are infected. We do plan to have another hearing on testing and counseling because we hope to move legislation on that issue.

But every hearing we've ever had on the question of AIDS, and no matter what aspect we're looking at—Mr. Dannemeyer's has pushed this point about mandatory reporting—and I just want you to know and for him to know, and others to know, that there is no Federal mandate for any disease—syphilis, malaria, any disease—to be reported, a list to be kept for contact tracing to be done by the States.

The States have chosen—all 50—that contact tracing for syphilis because there is a cure for syphilis. And if you wonder if this is a panacea for the problem, we're facing the highest syphilis rates we've had in 40 years. So it's hard to imagine that keeping the names of people—and you wonder why some people want to keep those names—but keeping the names of people is suddenly going to prevent the disease from spreading, or keeping the names of people is suddenly going to prevent AIDS from developing for those who are infected.

The most shocking thing you've had to say today to me is that there is no national policy on AIDS. After 10 years, there is no Federal policy.

You came out with a report with a number of recommendations, and as I recall, President Reagan shifted that over to a commission to look at it further; and that commission came out with recommendations, and then Vice President Bush endorsed all those recommendations and said that he would recommend them when he became President. Yet we haven't seen the recommendations from

the Bush administration for those commissioned recommendations, which I recall were to make sure that every drug addict had access to a drug treatment program; to make sure that we had health care for those people who needed it; to make sure that we are going to prevent this disease through a broad education policy.

What have we done, since we don't have a vaccine to stop the spread of this disease, what we have done? And have we done an adequate job in using education as a means—and as our only means—to stop the spread of the disease?

Do we have a national policy there?

Mr. KOOP. We have a national policy on education, sir. I don't think it is as tight as it could be, and its results have been disappointing. I think that when 1987, and then everybody would agree that teenagers—which was the target group that year—never heard such explicit, repetitive advice about how to avoid sexually transmitted disease, of which AIDS was one, and is fatal.

And yet in 1988, infectious syphilis and penicillin-resistant gonorrhea rose in the 14- to 17-year-old group at a higher rate than it done in the previous 15 years.

So there are certain target groups that we have not been successful with and I think we have to do something more innovative and creative in the future than we have in the past.

Mr. WAXMAN. You are absolutely right and we'll look forward on this committee as we have in the past years to try to develop that policy with the administration, with all the responsible people in government.

I think it's more incumbent upon us than ever before that we try to figure out what is the appropriate national response to this serious epidemic. And as we develop this national approach, I know that we're going to go back to your recommendations and to your words and so many of your predictions that have unfortunately proved correct, because they have been predictions of this epidemic spreading.

I thank you very much for coming here today and your continued leadership in this issue.

Mr. KOOP. Thank you, sir.

Mr. WAXMAN. For the next witnesses I want to point out, as I ask them to come forward, one of the unfortunate myths about HIV AIDS epidemic is that it is a problem limited to New York and San Francisco. In fact, the epidemic has already hit many other cities as well. While the populations affected by the epidemic seem to differ from city to city, there is one common theme: In each high incidence community, a small handful of hospitals and practitioners is treating the majority of the individuals with AIDS. Often these are public hospitals, traditionally with the providers of last resort, but in many cases private nonprofit hospitals are heavily involved.

Our next panel is composed of representatives from three hospitals that serve a large volume of AIDS patients. They are going to tell us what the epidemic looks like in their community, how their institutions are coping, and what the Medicaid program can do to help.

Barbara King Loyd is the Administrator of the South Florida AIDS Network at Jackson Memorial Medical Center in Miami. In



1987, the most recent year for which we have data, Jackson Memorial had the largest number of AIDS admissions of any hospital in the country.

Robert Parrish is the Associate Director, Grady Memorial Hospital in Atlanta. In 1987, Grady ranked 16th among all hospitals in terms of AIDS admissions. On a personal note, Grady is also the hospital where Allison Leland's twin boys, Cameron George and Austin Mickey, were born on January 14, 1990.

Richard Conviser represents the Children's Hospital of New Jersey in Newark, and he is with us as well to talk about the AIDS impact in his community.

We want to welcome the three of you to our hearing today. Your prepared statements are going to be in the record in full. What we would like to ask each of you to do is to limit your oral presentation to no more than 5 minutes.

Ms. Loyd, why don't we start with you?

**STATEMENTS OF BARBARA KING LOYD, ADMINISTRATOR, SOUTH FLORIDA AIDS NETWORK, JACKSON MEMORIAL MEDICAL CENTER, ON BEHALF OF THE NATIONAL ASSOCIATION OF PUBLIC HOSPITALS; ROBERT L. PARRISH, ASSOCIATE DIRECTOR, GRADY MEMORIAL HOSPITAL, ON BEHALF OF THE NATIONAL ASSOCIATION OF PUBLIC HOSPITALS; AND RICHARD CONVISER, CONSULTANT, CHILDREN'S HOSPITAL AIDS PROGRAM, CHILDREN'S HOSPITAL OF NEW JERSEY**

Ms. LOYD. Good morning, Mr. Chairman and members of the committee and the subcommittee, I am Barbara King Loyd. I am the administrator of the South Florida AIDS Network, which is operated by Jackson Memorial Medical Center in Miami, FL. I am pleased to have this opportunity to discuss the situation of our comprehensive AIDS program at Jackson Memorial Hospital, which primarily serves the indigent AIDS population in the Miami area.

I join my colleagues in urging you to adopt H.R. 4080, the Medicaid AIDS and HIV Amendments of 1990. I also endorse that you explore other ways to assist our public hospitals in coping with the challenge of confronting AIDS in the 1990s. The plight of public hospitals cannot be emphasized too strongly.

As you will hear in my testimony and from my colleagues this morning, these safety net institutions are assuming an increasing share of the burden of treating AIDS patients, at a time when the number of patients itself is increasing.

I would like to highlight the fact that you just mentioned that Jackson has admitted more AIDS patients than any other hospital in the United States. According to the 1987 U.S. Hospital AIDS Survey released last August, Jackson Memorial Hospital admitted 999 AIDS patients in 1987. These patients account for 999 admissions and a total of 13,405 inpatient days. This makes Jackson Memorial Hospital the highest volume admitter of AIDS patients in the country in 1987, and preliminary 1988 data now being analyzed indicates that we will likely retain that dubious honor.

As a State, Florida has maintained its rank of third in the Nation of actual number of reported AIDS cases since the begin-

ning of the epidemic. Currently, Florida has 9,799 cases of adults since December 1, 1989. It also maintains its rank of second in States of the largest number of pediatric AIDS cases—277. We have a combined total cases of over 10,000.

Almost 32 percent of all cases of AIDS in Florida occur in Miami. Miami has the largest cumulative number of cases of AIDS in Florida—3,082.

Dade County—unique demographic pattern—more closely reflects the pattern of AIDS as it will probably develop nationally in the future. Forty-nine percent of the cases occur in homosexual/bisexual men and 17 percent in intravenous drug users. Eight percent are in both, homosexual/bisexual men using intravenous drugs.

Strikingly, though, 19 percent of Dade's cases are heterosexually transmitted. In cases of pediatrics, 50 percent of all Florida cases occur in Dade County. Seventy-three percent of cases occur in blacks and Hispanics, 44 and 29 percent respectively.

In the past 5 years, South Florida AIDS Network has developed a remarkable response to the crisis of the AIDS epidemic under the leadership of Jackson Memorial Hospital of Dade County, FL. In place or under development are major components of a comprehensive system of care for men, women, and children with HIV disease. Indeed, the region has well demonstrated that it can meet the challenge of service development on the crisis.

The epidemic will not abate in the foreseeable future, but through the efforts of the hospital and the South Florida AIDS Network, it's character of crisis has been tamed to one of manageable anxiety.

The provisions of health care to this rapidly growing patient population is an industry-wide dilemma with resources unable to keep pace with the demand.

South Florida AIDS Network of Miami is by far the largest of the AIDS care and treatment networks in Florida and is centered around Jackson Memorial Hospital. Despite major accomplishments in the development of new resources, a fundamental dilemma exists for Jackson—the steadily increasing utilization of resources by a steadily increasing number of AIDS patients; the combination will soon overtax the system.

When conceptualized in 1986, the South Florida AIDS Network was designed to serve 600 AIDS patients. By October of 1989, 5,000 patients have been enrolled in the program.

Some of our problems is that the dedicated 35-bed inpatient unit at Jackson Memorial Hospital is routinely filled and AIDS patients are hospitalized on all floors of the hospital. The daily census approaches 80.

Jackson provides approximately 65 percent of all acute care to persons with AIDS or AIDS-related illnesses. A separate dedicated six-bed unit for pediatric cases was also developed. The average daily census is 8 to 10 cases.

JMH—Jackson Memorial Hospital—provides outpatient clinical services at a special immunology clinic located on the Jackson complex. Twenty-eight adult clinics and eight for children are held monthly. An average of 280 patients are seen monthly. Due to de-

mands on the clinic, there is an average waiting time for services of 6 months for new patients. There's no time waiting for children.

Frequent patients needing care and access present themselves in the emergency room to get the needed medical attention. The patient can be seen and treated or admitted directly to the inpatient setting. This is a more expensive route to care for outpatient clinical service patients.

Mr. WAXMAN. Thank you, Ms. Loyd. The rest of that statement is going to be in the record, and we appreciate your presentation to us.

[The prepared statement of Ms. Loyd follows:]



## NATIONAL ASSOCIATION OF PUBLIC HOSPITALS

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STATEMENT of BARBARA KING LOYD

SOUTH FLORIDA AIDS NETWORK

JACKSON MEMORIAL MEDICAL CENTER

on behalf of the

NATIONAL ASSOCIATION OF PUBLIC HOSPITALS

before the

HOUSE ENERGY and COMMERCE COMMITTEE

SUBCOMMITTEE on HEALTH and the ENVIRONMENT

February 27, 1990

Mr. Chairman, Members of the Committee and Subcommittee, I am Barbara King Loyd. I am the Administrator of the South Florida AIDS Network, which is operated by Jackson Memorial Medical Center (Jackson) in Miami, Florida. I am pleased to have this opportunity to discuss the situation of our comprehensive AIDS program at Jackson, which primarily serves the indigent AIDS population in the Miami area.

I join my colleague Robert Parrish, of Grady Memorial Hospital, in urging you to adopt H.R. 4080, the "Medicaid AIDS and HIV Amendments of 1990". I also endorse his message to you that we must explore other ways to assist our public hospitals in coping with the challenge of confronting AIDS in the 1990s. The plight of public hospitals cannot be emphasized too strongly. As you will hear in my testimony and from my colleague this morning, these safety net institutions are assuming an increasing share of the burden of treating AIDS patients, at a time when the number of patients itself is increasing. Moreover, in his fiscal year 1990 budget, the President has proposed \$5.5 billion cuts to Medicare, \$4.1 billion of which would come from hospitals. Mr. Chairman, I hope the example of the comprehensive AIDS program developed by Jackson Memorial Medical Center in Miami, that I am here to tell you about today, will illustrate how one public hospital is confronting this formidable challenge.

As you have just learned from my colleague Robert Parrish, Jackson has admitted more AIDS patients than any other hospital in the United States. According to the 1987 U.S. Hospital AIDS Survey released last August, Jackson admitted 799 AIDS patients in 1987. These patients accounted for 999 admissions and a total of 13,405 inpatient days. This made Jackson Memorial

Denver General Hospital  
Boston City Hospital  
District of Columbia General Hospital  
Harris County Hospital District (Houston)  
University of Medicine and Dentistry  
of New Jersey University Hospital  
Grady Memorial Hospital (Atlanta)  
Santa Clara Valley Medical Center (San Jose)

THE LOS ANGELES COUNTY HOSPITALS:  
Harbor UCLA Medical Center  
High Desert Hospital  
M.L. King Drew Medical Center  
LAC-USC Medical Center  
Olive View Medical Center  
Rancho Los Amigos Medical Center  
Parkland Memorial Hospital (Dallas)  
Truman Medical Center (Kansas City)  
San Francisco General Hospital

NEW YORK CITY HEALTH AND  
HOSPITALS CORPORATION:  
Bellevue Hospital Center  
Bronx Municipal Hospital  
City Hospital at Elmhurst (New York City)  
Coney Island Hospital  
Harlem Hospital Center  
Kings County Hospital Center  
Lincoln Medical and Mental Health Center  
Metropolitan Hospital Center  
North Central Bronx Hospital  
Queens Hospital Center  
Woodhull Medical and Mental Health  
Center (New York City)

Cook County Hospital  
Contra Costa County Health Services  
Department  
Brackenridge Hospital (Austin)  
Wishard Memorial Hospital  
(Indianapolis)  
Alameda County Health Care Services  
Agency (Oakland)  
Westchester County Medical Center  
Milwaukee County Medical Center  
Nassau County Medical Center  
Regional Medical Center at Memphis  
University of New Mexico Hospital  
Harborview Medical Center, University  
of Washington  
Fresno County Valley Medical Center  
R. E. Thomson General Hospital  
Kern Medical Center (Bakersfield)  
University of Cincinnati Hospital  
University of Texas Medical Branch  
Hurley Medical Center (Flint)  
San Bernardino County Medical Center  
Riverside General Hospital,  
University Medical Center  
Spartanburg General Hospital  
Charity Hospital at New Orleans  
Maricopa Medical Center (Phoenix)  
St. Louis Regional Medical Center  
Memorial Medical Center (Savannah, GA)  
Amarillo Hospital District  
Jackson Memorial Hospital (Miami)  
Pontiac General Hospital (Pontiac, MI)  
St. Paul-Ramsey Medical Center

LOUISIANA OFFICE OF HOSPITALS:  
E. A. Conway Memorial Hospital  
(Monroe, LA)  
Earl K. Long Memorial Hospital  
(Baton Rouge)  
Huey P. Long Memorial Hospital  
(Fresnoville, LA)  
Lalib-Kemp Charity Hospital  
(Independence, LA)  
Moss Regional Hospital (Lake Charles, LA)  
University Medical Center (Lafayette, LA)  
Washington St. Tammany Charity  
Hospital (Bogalusa, LA)

Tampa General Hospital  
Erie County Medical Center (Buffalo)  
Prince George's Hospital Center (MD)  
University Hospital (Omaha, NE)  
Quincy City Hospital (Quincy, MA)

the highest volume admitter of AIDS patients in the country in 1987, and preliminary 1988 data now being analyzed indicates that we are likely to retain that dubious honor.

In addition, Jackson Memorial treated 1,019 AIDS outpatients during 9,557 visits for that year. To accomodate this staggering demand on Jackson's resources, my colleagues spearheaded the development of a comprehensive AIDS program in an effort to coordinate the myriad of AIDS services available to people in the Miami area, especially the indigent population. The South Florida AIDS Network (the Network) is the result of the efforts of many dedicated health care professionals in Miami.

Operated through offices at Jackson, the Network offers patient advocates and social workers who, along with discharge planners, combine their efforts in a unique program that attempts to ensure that each individual receives services to meet medical, social and personal needs. As of December 1, 1989, 5,200 clients have been enrolled in the Network. Set forth below is a description of the wide variety of services provided by the Network, as well as a review of both the Network's budget and utilization of Network services.

#### Inpatient Acute Care Services

Jackson Memorial Medical Center is the only publicly funded hospital in Dade County. Jackson provides approximately 60% of the inpatient acute care to persons with AIDS (PWAs) and/or related illnesses. A dedicated adult AIDS Unit has been established with a 35-bed capacity. A separate pediatric unit consists of six beds. The inpatient pediatric population with AIDS-related illness averages eight to ten patients daily. The inpatient adult population averages 65 to 70 per day.

#### Outpatient Clinical Services

Outpatient clinical services are provided at the Special Immunology/Oncology Clinic located at Jackson. Services provided range from diagnostic and medical treatment, nutritional guidance, nursing, dental care, obstetrical care, education, prescription/medication dispensing, laboratory services and spiritual/pastoral support. An average of 280 patients are seen monthly. Twenty-eight clinics are held monthly for adults and eight for children. As of January 1, 1990, there is an average waiting time for services of six months for a new adult patient to be seen. There is no waiting period for children.

#### Primary Care

The Network has negotiated with six primary care centers to provide diagnosis, treatment, and counseling referrals to individuals with AIDS/ARC in order to more effectively meet their

primary care needs. Patients are managed by the primary care centers until their symptoms become too complicated for center staff. A referral to the Special Immunology Clinic is then made. Once the condition is stabilized, the patient returns to the primary care center for ongoing care. Support from the Florida (State) Care and Treatment Program provides each center with an AIDS Coordinator as well as reimbursement for clinic visits and prescriptions.

#### Home Health Services

Home health services are provided to Network clients through the Visiting Nurse Association (VNA). VNA provides a comprehensive community-based system of care. The services provided depend upon the need of the patients as prescribed by the patient's physician. Skilled nursing visits range from four times a day to once a month. The nurses assess the patient's medical condition and home situation. In addition, they provide symptom management and supportive care. High-tech nursing services include drug infusion therapy and related procedures. Home health aides provide personal care and assistance with activities of daily living. Homemakers prepare meals and do light housekeeping and grocery shopping. In addition, VNA provides durable medical equipment such as wheelchairs, hospital beds, oxygen and walking devices.

#### Hospice Services

Hospice provides care for AIDS patients who are in the end stage of their disease and no longer require aggressive therapy. Home care is available to individuals who have the support of family or friends who will assist in their care and attend to their daily needs. Inpatient services are available to individuals who can no longer be maintained at home. A 15-bed inpatient unit is located at North Shore Hospital in Miami. There is an average of six AIDS patients per month. Services include: skilled nursing care, nurses aides services, homemaker services, personal care, medical supplies, prescribed drugs and durable medical equipment, case management, pastoral support, bereavement counseling, and respite care. Between October 1988 and September 1989, Hospice, Inc., of Dade provided services for 213 patients. 115 of these patients were registered with the Network.

#### Psychosocial Counseling

Psychosocial counseling is provided by Health Crisis Network (HCN), the Children's Home Society, the Haitian American Community Association of Dade (HACAD) and the League Against AIDS (LAA). These organizations provide counseling to persons with HIV, AIDS, and AIDS-related conditions, as well as their families, significant others and friends. The last two organizations provide culturally sensitive counseling for

Haitians and Hispanics. Group and individual counseling is also available.

#### Mental Health and Substance Abuse Services

The Network has negotiated with three community mental health centers (CHI, North Miami and Miami Mental Health Center) to provide individual and group counseling for PWAs with dementia on an outpatient basis. There is no residential mental health facility in Dade County which will treat PWAs. Moreover, no residential detoxification facility is currently providing services to PWAs. However, three mental health providers (CHI, North Miami Community Health Center and HCN) provide outpatient counseling to PWAs who are substance-abusers.

#### Case Management Services

A uniform case management system is still in the expansion phase at the Network. In addition, case management is being coordinated through the Network with respect to VNA, HCN, Hospice Inc., and other Network agencies. The Network has a number of patient advocates who are involved in centralized case management and who provide access to needed Network services, assistance in meeting eligibility requirements for financial and social services, and assistance in obtaining housing and transportation.

#### Food Assistance Program

Currently, Cure AIDS Now is providing meals to a limited number of PWAs. Funding for this service is provided by Metro-Dade County, the City of Miami and the City of Miami Beach. Although not funded by the Network, several community agencies utilize this home delivered meals program to serve Network patients. HCN is presently starting a nutritional program. In addition, the Network recently requested proposals to establish two nutrition coordinator positions funded through the new federal Health Resource Services Administration (HRSA) grant.

#### Long-Term Inpatient Care Services

At the present time, the Human Resource Health Center (HRHC) is the major provider of nursing home services in Dade County for PWAs. HRHC was the first nursing home in the nation to accept AIDS patients and currently has 17 beds available to this population. They provide specialized skilled and comprehensive nursing care for AIDS patients who cannot remain at home due to the extent of their condition and/or lack of necessary support systems. There is presently an average of four to five beds empty on a daily basis. Individuals referred to HRHC must be Medicaid eligible, medically needy, and have a discharge plan from the referring source. HRHC was awarded a Certificate of



Need (CON) to construct a 30-bed AIDS unit. Present plans are for the facility to open by August of 1990.

Additionally, Careage South Health Center was awarded a CON to construct a 120-bed nursing home which would have provided up to 25 beds for AIDS patients. Unfortunately, this CON was voided July 11, 1989 due to lack of progress by Careage South Health Center.

#### Residential Facilities

An organized system of residential care for adults with AIDS and/or AIDS-related conditions has not been fully developed due, in part, to complicated licensure rules and procedures. However, limited residential care is being provided by the Salvation Army, Camillus House and Genesis through the Metro Dade Office of Emergency Assistance of the Department of Human Resources. The Salvation Army operates a temporary shelter for four to six PWAs on an emergency basis for seven to ten days until a residential plan is developed by the Metro Dade Office of Emergency Assistance (OEA). OEA identifies hotels, motels, and apartments where PWAs can be housed and assists PWAs in negotiating leases. The facility provides transitional care between hospitals and home. A comprehensive care program (prevention, education, counseling, and spiritual support) for individuals who function fairly independently is also provided. As patients become more debilitated, home health services can be provided through contracted agencies.

The Outreach Program of Hospice, Inc. received a specific line item appropriation of \$100,000 from the State for fiscal year (FY) 89-90. This funding will provide financial assistance to individuals living with AIDS to remain in their current place of residence or to support an alternate placement for those who meet eligibility requirements.

In addition to agencies that have formal agreements with the Network, community-based organizations such as HCN often make some limited arrangements for residential care. Cure AIDS Now recently started renovations on a building which will provide additional housing for their clients.

A foster care program has been developed by the Network through the Department of Health and Rehabilitative Services (HRS) and the Children's Home Society (CHS). Since the program began, 40 children have been placed. Currently, there are 20 licensed foster homes. CHS recruits and provides training for foster parents, holds support group sessions and provides education and counseling for family members of children with HIV. There are more foster parents available than there are children needing placement.

### Volunteer Services

Volunteers are vital to the success of any patient care and treatment network. HCN maintains an active group of approximately 120 trained volunteers who provide 12,000 hours of services annually to our patient population. They perform many functions, such as providing transportation, operating hotlines, shopping and other household duties, and providing emotional and other supportive care. A volunteer coordinator is responsible for recruitment and training of volunteers. Every volunteer participates in a 32-hour training program. A support group is provided for them to reduce stress, anxiety and emotional burnout. In addition, Hospice, Pastoral Care Network, Cure AIDS Now, Body Positive, Genesis, Share A Gift, and Project Hug have volunteer services.

### Information and Referral

The Network's operations office provides information to individuals regarding the enrollment process and the services available in the Miami community, as well as makes referrals to community agencies. Each Network member is provided information and a referral. Other community agencies (HCN, HACAD) have hotlines which provide referrals and information to PWAs, their families and to the general public.

### Transportation Services

Transportation to and from medical appointments and social service agencies are provided to Network clients through contracted agencies. HCN, HACAD, and LAA each have \$5,000 available to their agency for client transportation needs. Diamond Cab Company has also provided transportation in the interim. For FY 89-90, Jackson will be the major provider of transportation services.

### Testing, Surveillance and Special Studies

The HRS Dade County Public Health Unit (DCPHU) has a centralized AIDS office that coordinates all AIDS services provided by the public health unit throughout the county. These services are organized by functions: surveillance, testing and counseling, special studies, and primary care. The local public health unit has the responsibility to report confirmed cases of AIDS to the Centers for Disease Control (CDC), train physicians and hospitals in reporting procedures and partner notification. Testing is done through two anonymous testing sites. Confidential testing is done at all clinics. Pretest and test result counseling is provided. This counseling is limited to information on referral sources and test results. Special studies are being conducted which focus on seroprevalence and perinatal infection. Primary

health care will soon be available at the DCPHU South Beach facility.

#### Community Hospitals

Several community hospitals treat a significant number of patients with AIDS or ARC. Data from HCCB for three months of 1987 showed that there was a total of 492 admissions for 22 hospitals in Dade County. Jackson had 284 (58%) of the total admissions. Information for FY 88-89 is partly available from seven hospitals. By comparing the total number of hospital admissions for FY 87-88 (1248) with the number of admissions for FY 88-89 (1545), one can appreciate the dramatic increase in service volume for inpatient care.

#### Budget

The Public Health Trust/Jackson Memorial Hospital (PHT/JMH) is the major recipient of all funds for the South Florida AIDS Network. This includes non-state funds which are specifically allocated for Broward and Monroe Counties. The Network receives its funding from the State of Florida, Robert Wood Johnson Foundation (RWJ) and HRSA. Unlike other counties, Dade County does not receive state funding from the State Care and Treatment Program based on the number of AIDS cases reported. A line-item appropriation is determined by the legislature.

For FY 1987-88, the total approved budget for the Network was \$7,904,516 and, for FY 88-89, \$9,254,815. This does not include any funds contributed by PHT/JMH from other sources. The majority of the budget, however, is funded by the State Care and Treatment Program. In FY 87-88, reported Medicaid reimbursement totaled \$3,243,111, and other third party and self-pay reimbursement totaled \$1,966,541. Of the \$13,803,511 budgeted for care and treatment of PWAs in Dade County for FY 87-88, 44% was funded by State Care and Treatment funds, 23% by Medicaid, 18% by the JMH/PHT and 14% by other sources.

Expenditure rates for FY 87-88 varied according to grant. The state care and treatment budget was overspent by 138%. Jackson funded \$2,550,140 of the over-expenditure from other sources. The expenditure rate was 85% for RWJ and 78% and 33% for the HRSA grants. The amount reimbursed by third party payors such as Medicaid, commercial insurance and other sources is not included in the budget.

The budget for the Network for FY 88-89 was \$9,254,815. The State provided funds for 73% of the total. HRSA provided 21% and RWJ provided 6% of the funding. Amounts paid by third party payors such as Medicaid, private insurance and others, were not included.

The cost of financing the Network has consistently exceeded its annual budgets. Expenditures for FY 88-89 totaled \$11,959,291 which is 175.9% of the State Care and Treatment Program budget. Inpatient care reflected a 54% expenditure for the total Care and Treatment budget. This category was 323.9% over the approved line item of \$2,000,000 budgeted. It is assumed that not all of the \$4,478,481 in excess of the budget total will be charged off to the Care and Treatment Program. Other line items that were over budget include the Outpatient Clinic (171.1%), Emergency Room (643.7%), Residential Care for children (123.8%) and Physician Care (185.5%). These expenditure rates are based on approved line items expenses for FY 88-89.

Expenditures for the first quarter of FY 89-90 total \$2,653,355 or 39% of the total approved budget of \$6,800,000 for State Care and Treatment. This is already beyond the 25% expenditure rate expected. Inpatient care reflected 47% of the expenses for this period. Other line items over the approved budget include children (34.9%) and adult (37%), Residential Care, Outpatient Clinic (47.3%), Emergency Room (191.9%), Physician Care (59%) and Patient/Staff Education (48.5%).

#### Utilization of Services

During FY 88-89, a total of \$31,558,289 worth of services were provided to Network patients. \$11,393,482 (36%) was charged to the State Care and Treatment Program. Medicaid paid 26% and other sources (commercial insurance, private pay, medicare, etc.) paid 38%. A total of 142,616 units of service (inpatient days, outpatient visits, home health visits, psychosocial counseling, etc.) were provided to patients.

For the first quarter of the FY 89-90, a total of \$6,570,243 worth of services were provided. Over one third (\$2,471,644) of the total charges were billed to the State Care and Treatment Program. Not all of this amount will be approved. Medicaid paid \$1,890,974 (29%) of the total charges. Other sources (insurance, private pay, Medicare, Jackson uncompensated care) amounts to \$2,193,625 or 33% of the total. 42,263 units of service were provided to Network patients during this three month period.

Mr. Chairman, I thank you for this opportunity to tell you about the Network, Jackson's comprehensive AIDS program. I also thank you, and your staff, for your consistent concern with the tragedy of AIDS, and the plight of public hospitals in coping with this tragedy. I do want to emphasize that public hospitals need much more support in meeting this challenge--support that extends beyond AIDS adjustments to other enhancements of Medicaid. However, I hope that the example of the comprehensive AIDS program at Jackson will demonstrate that with your help our public hospitals are well up to the task of confronting AIDS.



Mr. WAXMAN. Mr. Parrish.

# STATEMENT OF ROBERT L. PARRISH

Mr. PARRISH. Good morning, I'm Robert Parrish. I'm an Associate Director of Grady Memorial Hospital in Atlanta. Grady is the public hospital that serves the counties of Fulton and DeKalb that make up Atlanta, and those two counties have a population base of almost one-fourth of the State of Georgia.

In the AIDS program at Grady we're treating 1,021 adults and 43 children. We are following up on another 100 children who were born to mothers who are HIV positive but the babies do not yet test positive.

Out of the approximately 1,000 adults, about 40 to 50 are hospitalized at any given time, so this is 4 to 5 percent of HIV infections that the hospital is following. Of this number, 13 percent qualify for Medicaid easily, and an additional 17 percent may eventually qualify for Medicaid, so something in the neighborhood of 30 percent of our patients may ultimately be qualified for Medicaid.

The disturbing number is that the largest percentage of our patients, 56 percent do not qualify for any kind of third-party reimbursement. They have no coverage whatsoever so their care is picked up by the local property tax of the two counties that support the hospital.

Historically, Grady Hospital, like most other public hospitals, is insistent on being in the control position, being in the driver's seat in determining what kinds of care programs are delivered to its patients and when those are delivered.

About 5 years ago, when we were in the early stages of the AIDS epidemic in Atlanta, we made a determination to try to build on the hospital's strength in developing outpatient programs on a very aggressive level and to join with two community-based agencies—Aid Atlanta and Visiting Nurse Association—in a partnership for caring for people with AIDS.

As a result of that decision the three agencies applied to the Robert Wood Johnson Foundation and subsequently to HRSA to develop a continuum of care for dealing with patients who have an HIV positive infection and for evaluating the effectiveness of that approach.

The system that we have in place involves case management done by the community-based agency—Aid Atlanta—backed up by a comprehensive outpatient clinic at Grady Hospital, which is staffed by faculty level, infectious disease, medical staff members, nurse practitioners, social workers, and other therapists.

The inpatient beds are used when necessary when the outpatient care cannot handle the patient's problem.

We also have as a part of this continuum a home care program run by the Visiting Nurse Association and a Hospice run by Visiting Nurse and by the hospital.

The program has been so successful, but at the present time we are lobbying the State Legislature to pick up the expiring Johnson and HRSA grants. If these agencies are not able to continue to do case management and continue to do home care, then those tasks will fall to the hospital. We don't have the staff to do case manage-

ment and we don't have the beds to hospitalize an additional 20 patients, which would need inpatient care, if the home care programs were disbanded.

In looking at the population in our AIDS clinic, we have a significant number of people who are in our clinic because they have been fired from their jobs when the employer discovered they were HIV positive and, therefore lost their insurance coverage.

These are people who are able to work and who are being cared for in the public sector simply because the employer, for whatever reason, has decided to terminate the employment of that individual. That seems to us to be an unnecessary burden being placed on the public sector when there are private physicians and private hospitals in our city who are able to deal with these patients.

The greatest problems that Grady is facing in dealing with the AIDS epidemic or we have a 5- to 6-week delay in getting into our clinic, during that period sometimes the individuals who have been accepted for care but are not yet in the clinic have to come to the emergency clinic for care and wind up being hospitalized.

A second problem is we are full in all of our ambulatory and all of our inpatient facilities. We don't have any expansion space for additional AIDS patients and we will not for the next 5 years.

A third problem we have in Georgia is that nursing homes do not accept patients with HIV infections. At any given time we have about 30 percent of our inpatients who could be cared for well in a nursing home situation, either skilled or custodial. And they are not able to be handled because the facilities are not there.

The local tax base is projected to provide to Grady Hospital from the two counties that make up Atlanta \$248 million in 1996. This projection is exclusive of AIDS epidemic. This is an awful lot of money for two counties in Georgia to be providing to one public hospital. So it seems apparent to us that we are going to need to be looking for some outside help in continuing to deal with the epidemic.

Mr. WAXMAN. Thank you very much, Mr. Parrish.

[Testimony resumes on p. 68.]

[The prepared statement of Mr. Parrish follows:]

STATEMENT of ROBERT L. PARRISH  
ASSOCIATE DIRECTOR  
GRADY MEMORIAL HOSPITAL  
on behalf of the  
NATIONAL ASSOCIATION PUBLIC HOSPITALS  
before the  
HOUSE ENERGY and COMMERCE COMMITTEE  
SUBCOMMITTEE on HEALTH and the ENVIRONMENT

February 27, 1990

Mr. Chairman, Members of the Committee and Subcommittee, I am Mr. Robert Parrish, Associate Director of Grady Memorial Hospital in Atlanta, Georgia. Grady Memorial is a member of the National Association of Public Hospitals (NAPH). NAPH consists of approximately 90 public and non-profit hospitals that serve as major referral centers, teaching hospitals, and hospitals of last resort for the poor and medically underserved in most of our nation's largest metropolitan areas.

Mr. Chairman, I am pleased to have this opportunity this morning to commend you for your hard work on H.R. 4080, the "Medicaid Aids and HIV Amendments of 1990", and to personally thank you and your staff for your continuous concern with the problem of AIDS, and the attendant problems that AIDS has created for public hospitals in this country. I am also pleased to discuss with you the pressing problems faced by Grady Memorial Hospital, and other NAPH member hospitals, in meeting the needs of persons with HIV-related diseases.

My principle purpose this morning is to vigorously urge the adoption of H.R. 4080. I am deeply gratified that you have understood the urgent need to extend optional coverage of HIV-related services to certain HIV-positive individuals, to adjust payments to hospitals serving high volumes of AIDS patients, and to extend optional coverage for home and community-based services to certain children with AIDS. I particularly applaud the proposal to provide federal Medicaid assistance for COBRA premium payments for HIV-positive individuals.

However, I also want to take this opportunity to explain that while these adjustments in Medicaid coverage for persons with AIDS (PWAs) and certain HIV-positive individuals, are badly needed, many further enhancements of Medicaid reimbursement for AIDS services are required if public hospitals are to meet the challenge that this patient population poses.

Indeed Mr. Chairman, as you know only too well, the emergence of AIDS as an epidemic in the 1980s has been paralleled by the emergence of new and formidable treatment burdens placed on the U.S. health care system. As the numbers of those affected by this disease have risen, the mounting unreimbursed costs and resources expended in caring for PWAs have become glaringly apparent. According to the Center for Disease Control (CDC), AIDS has become the sixth leading cause of death among younger



people nationwide. By the early 1990s only motor vehicle accidents may cost more in terms of medical care.

We continue to see ominous signs that AIDS is becoming a disease primarily of the medically disenfranchised populations including the uninsured, underinsured, poor children and drug users. Although steps are being taken to expand the scope of services available to PWAs and HIV disease, for the most part the locus of care has remained in the hospital. While increasing numbers of hospitals are treating these patients, the very nature of this population dictates that the nation's safety net institutions--the public hospitals-- are the group most likely to treat this disenfranchised patient population.

It is important for the Committee to realize that AIDS is not just a problem confined to New York and California. Among the 25 hospitals with the greatest number of AIDS admissions nationwide in 1987 were hospitals located in cities such as Atlanta, Miami, the District of Columbia, Baltimore, San Diego, Dallas, Houston and Chicago. In fact, Miami's Jackson Memorial Hospital was ranked first among all hospitals in terms of total admissions. Grady Memorial was ranked 16th.

#### A. U.S. Hospital Aids Survey

Grady's difficulties in financing and providing hospital care to AIDS patients are typical of the experiences of many other NAPH member hospitals. Since 1986, the National Public Health and Hospital Institute, a research institute affiliated with NAPH, has been conducting the U.S. Hospital AIDS Survey to monitor treatment, financing and other factors related to caring for HIV-infected individuals. With the financial support of the Robert Wood Johnson Foundation, the initial Survey involved the 465 members of NAPH and the Council of Teaching Hospitals. Since then, the Survey has attracted additional support from the CDC, the Agency for Health Care Policy and Research, and the Bureau of Maternal and Child Health, and has grown to represent a 1200 hospital coalition of several associations, including the National Association of Children's Hospitals and Related Institutions, the National Council of Community Hospitals, the Catholic Health Association, as well as NAPH and the Council of Teaching Hospitals.

Set forth below is a summary of the 1987 Hospital AIDS Survey results. A more detailed presentation of the 1987 Survey results appeared in an article published last year in the Journal of the American Medical Association, which I have attached to my written statement. I am also privileged to present some

preliminary findings of the 1988 Hospital AIDS Survey based on information provided by 58 NAPH members.

#### PWA Utilization of Hospital Services

Most notable about the results of the 1987 Survey was the discovery that a major concentration of PWAs are admitted in relatively few institutions. Ten percent of the hospitals treated 58% of the patients, with 10 hospitals treating 32% of the PWAs. In total, of the 322 hospitals responding to the Survey, 276 reported that they had treated at least one AIDS patient in 1987. The 14,145 PWAs treated by these hospitals accounted for 371,768 inpatient days and 22,088 admissions, and represented 52% of the 27,126 PWAs in the United States estimated by the CDC to be alive at any one time during 1987. These hospitals tend to be large urban hospitals that are publicly owned.

The institutions treating AIDS patients admitted an average of 51 AIDS inpatients per year (the range was from 1 to 799), and reported an average of 1.6 admissions per patient per year. The average patient received 26 days of inpatient care, with an average length of stay (ALOS) of 16.8 days per admission. With respect to outpatient services, 85 hospitals identified treating 7,602 AIDS outpatients during 1987, an average of 89 per institution. They accounted for 61,897 visits, which equalled

8.1 visits per person per year and 728 visits per facility per year.

Although specific figures are not yet available, the Survey indicates that patients demanding AIDS services among these hospitals is not limited to PWAs. Patients who are infected with the AIDS virus, but do not manifest the requisite symptoms to meet the CDC definition of AIDS, also represent a substantial burden on hospital services. Although HIV-infected patients generally do not require as many admissions as PWAs, the ALOS for the HIV-infected population is only slightly less than that of the AIDS patient. The Survey findings suggest that HIV-infected patients do not need inpatient hospital care as frequently as PWAs, but that, once admitted, their illness is sufficiently serious to require a hospital length of stay almost equivalent to a PWA.

AIDS hospital utilization characteristics varied across regions. Institutions in the Northeast reported treating the greatest number, 82 patients per facility. Public hospitals treated, on average, more than twice as many AIDS patients as private hospitals in 1987 (88 and 36, respectively). Public hospitals in the Northeast treated the greatest number per facility (164), followed by public institutions in the South (90).



There were no significant differences in ALOS overall among regions or between public and private hospitals. However, the northeastern public hospitals' ALOS (24.5 days) was significantly longer than public hospitals in the Midwest (13.7 days) and public hospitals in the South (13.8 days). Hospitals in the Northeast reported the highest number of days per patient per year, 31.4, and public hospitals in this region reported the highest of all categories, 35.2 days per patient per year.

Turning to the preliminary 1988 Survey findings, the 58 NAPH public hospital members reported treating almost 7800 AIDS patients during 1988 -- an increase of nearly fifty percent over 1987. ALOS was 17.5 days, and average admissions and days per patient per year were 1.7 and 29.3, respectively. Compared with the 1987 Survey results, this data reveals a slight decline in ALOS but an increase in days and admissions per patient per year. Early indications suggest that much of the increase in these measures is related to changes among public institutions in the Northeast. That is, while public hospitals in other parts of the country are demonstrating, in general, modest declines in per patient utilization, facilities in the Northeast are reporting sizable increases in the number of days an AIDS patient was hospitalized during 1988 and the frequency of admissions. In fact, ALOS increased as well in this region.

These early findings suggest that the hospitals in the Midwest, South and West continue to make modest progress towards containing the per patient-based utilization rates for AIDS patients. However, public institutions in the Northeast continue to encounter the greatest burden. At least three factors may be placing additional stress on providers in this region: a sicker patient population, a demographically poorer population with a high concentration of drug abusers, and the unavailability of long-term care placements and outpatient resources for AIDS patients following admission.

#### Demographics

Homosexual individuals with AIDS constituted the largest risk-group category of AIDS patients (54%), followed by heterosexual drug users (27%). Children of risk-group members constituted 6% of the PWAs reported. As expected, the great majority (85%) of AIDS patients fell within an age range of 20 to 49 years. Eight-five percent were male. By race, 46% were white, 35% black, and 17% Hispanic.

There were significant differences in the race and age proportions between regions and ownership categories. Public and private hospitals in the Northeast treated the lowest proportion of white AIDS patients of any categories (15% and 46%, respectively). Hospitals in the West treated the lowest

proportion (24%) of minority AIDS patients of any region or ownership group.

During 1988, the majority of AIDS patients treated in NAPH member hospitals were, like in 1987, between the ages of 20 and 49 (90%) and male (84%). These hospitals also continue to treat a predominantly minority population (63%), although a slightly higher percent of caucasian patients (5%) was reported for 1988 when compared with 1987. Risk groups for HIV infection were almost evenly divided between homosexuals and other categories of patients. When these 1988 estimates are compared with 1987 responses, it appears that the proportion of AIDS patients classified as homosexual has increased (10%). And while the total number of heterosexual drug users clearly increased, this group as a proportion of the caseload in member institution decreased (10%).

While these results will be examined further in subsequent analyses, one possible explanation for the changes could be that many homosexuals who had previously been using private institutions under their insurance policies or with their own funds, have now exhausted their benefits and/or resources. Many may also have become sicker. These situations, especially in combination, may have required such patients to increasingly rely on the public system.

Hospital Cost and Revenue

Hospitals responding to the 1987 Survey reported that Medicaid was the primary payor for 44% of all admissions and private insurers represented 29%. "Self-pay" and "other," categories that generally represent uninsured or indigent patients, accounted for 23% of the admissions. Medicare was the payor for 2% of admissions. Public hospitals admitted a significantly higher percentage of PWAs whose payor source was Medicaid (52% of admissions to public hospitals vs 31% of admissions to private institutions) and a higher proportion of self-pay/other (31% vs 13% for private hospitals).

According to the preliminary 1988 data, public hospitals are increasingly relying on Medicaid to finance inpatient care for PWAs. Sixty percent of patients treated for AIDS in NAPH institutions during 1988 were Medicaid recipients. This reflects an 8% increase over 1987. When it is recognized that "self pay" or "other" patients--who are generally uninsured or indigent--represent 26% of AIDS patients in these hospitals, and that only 8% of AIDS patients in these hospitals are privately insured, it is obvious that these public institutions are carrying the burden of treating low income patients with AIDS. The proportion of Medicare-covered patients remains low.

For 1987, inpatient costs averaged \$681 per day while revenues averaged 80% of costs at \$545 per day. Inpatient costs



per patient per year averaged \$17,910, and per admission costs were \$11,441. By contrast, hospital revenues averaged \$14,334 per patient per year and \$9,156 per admission. There were no overall statistically significant differences in cost per day or revenue per day by ownership. However, average public hospital losses (\$218 per day) were significantly higher than average private institution losses (\$92 per day). For public hospitals, as well as private hospitals, losses were significantly greater for AIDS patients, at \$136 per patient per day, than losses for other medical/surgical patients, at \$26 per day.

Outpatient costs per visit averaged \$237 (charges = \$287), while revenues, at \$63 per visit, represented 27% of costs. This ratio was much lower than the revenue/cost-per-visit average for non-AIDS outpatient services (\$93/\$130, or 72%). Costs per patient per year for outpatient services averaged \$1,943 and revenues were \$517. Public hospitals' average cost per outpatient visit was significantly higher than private hospitals' average cost. Public hospitals' average revenue per visit represented 14% of costs, compared with private hospitals' revenues, which represented 83% of costs. The resulting losses per visit (\$264 for public hospital visits and \$94 for private hospital visits) were significantly different.

### Regional Differences in Financing AIDS Services:

#### Problems in the South

The 1987 Survey reveals significant regional differences in financing hospital services for PWAs. Medicaid was a payor for significantly more AIDS admissions in western and northeastern institutions (55% and 54%, respectively). Eighteen percent of admissions to hospitals in the South were covered by Medicaid, the smallest percentage of all regions. Almost half (48%) of all admissions in southern hospitals were reported as self-pay/other admissions. Moreover, in the South, revenues per day for public hospitals were significantly lower (\$232) than those of private hospitals (\$687), and losses per day were significantly higher for public hospitals (\$386 vs. \$4 for private hospitals). Almost all comparisons of cost per day, revenue per day, and loss per day made between public hospitals in the South, and public hospitals in other regions demonstrated significant differences.

#### **B. The Problems of Grady**

The problems Grady Memorial Hospital has encountered in treating PWAs are typical of the problems experienced by other public hospitals in the South in treating AIDS patients. For example, AIDS patients encounter a five to six week delay before being accepted for treatment in Grady's outpatient AIDS clinic. This is because we do not have enough money to hire additional staff to accommodate a larger caseload. Sometimes, while the

patient is waiting to get into the clinic, he or she may experience a crisis situation that precipitates a visit to the emergency room and an inpatient admission. Without more support for our outpatient services, inpatient utilization will remain unnecessarily high, at great expense to our hospital.

During the early stages of the AIDS epidemic, Grady developed and approved an expansion plan so that more inpatient beds and clinic resources would be available to PWAs. The number of beds in the proposed expansion, however, is insufficient to care for the increased numbers of AIDS patients we now anticipate. In addition, there are no nursing home beds available to AIDS patients in the State of Georgia. At any given time, 30% of the AIDS patients who are in beds at Grady Memorial Hospital could be more appropriately cared for in either skilled or custodial nursing home beds.

Grady Memorial Hospital is fortunate in that it receives substantial local support for its care of indigent patients. Two counties, in particular, are supporting much of Grady's indigent care population. By 1996, their contributions are projected to be \$248 million annually. This is a very large amount of money for two counties in Georgia to be allocating to a public hospital. Moreover, this estimate excludes any special adjustment for increased utilization of AIDS services. While Grady has enjoyed excellent local support for the past 98 years,

local resources alone cannot cover Grady's costs in treating the AIDS epidemic. The need for more state and federal support to supplement local funding efforts will intensify as more PWAs are drawn to Atlanta and other population centers to find services that are unavailable elsewhere.

### C. Legislative Recommendations

Public hospitals in this country, such as Grady Memorial Hospital, clearly continue to bear an increasing burden of AIDS patients, with the vast majority of these often tragically ill patients requiring public sector support. While many of these facilities appear to be avoiding major increases in utilization--at least for now--hospitals in the Northeast continue to struggle with a rising demand for inpatient beds. Institutions in the South, on the other hand, are receiving minimal reimbursement for AIDS services, and consequently suffering enormous financial losses. To address these urgent issues we urge you to consider the following recommendations. Mr. Chairman, NAPH stands ready to assist you and your staff in addressing the very difficult challenge that AIDS poses for the American health care system.

1. The Medicaid inpatient adjustment rate for patients with AIDS and for HIV-positive individuals should be increased for hospitals serving a disproportionate number of AIDS patients.

It is absolutely essential that hospitals serving a disproportionate share of the AIDS population receive an upward adjustment of Medicaid reimbursement for AIDS services. These



hospitals are straining from lengthy and expensive admissions of patients who are HIV positive, not merely from treating those with full-blown AIDS. Accordingly, the adjustment should apply to admissions of any HIV-infected individual. This expansion of inpatient services covered under Medicaid should be mandatory.

2. Medicaid reimbursement for outpatient services must approximate treatment cost, and outpatient therapies such as AZT and aerosolized pentamidine should qualify for mandatory Medicaid coverage.

To provide appropriate care to the growing population of AIDS and HIV-positive patients, it is clear that we must shift the locus of care away from the inpatient bed to the outpatient and community settings. Experts agree that both patients and providers would benefit from such a shift. In many states with comparatively broader Medicaid programs, hospitals may receive higher reimbursement for inpatient care than for outpatient care. Unless Medicaid payment for outpatient services is adjusted to more nearly approximate treatment costs, hospitals may have little incentive to develop outpatient AIDS clinics like the one at Grady. Outpatient therapies, especially AZT and aerosolized pentamidine, should qualify for mandatory Medicaid coverage.

3. The federal government should take a more active role in providing incentives to the states to develop outpatient and community-based treatment programs.

The federal government should take a more active role in identifying and encouraging communities to adopt non-hospital-

focused AIDS treatment programs. We recommend that a national study be conducted to assess the need for and success of non-hospital based AIDS services providers, especially as drug-related care assumes increasing importance. To further encourage the development of community-based programs, we also recommend the relaxation of the Medicaid Home and Community-Based Waiver requirements.

Finally, in addition to AIDS-specific programs that your Committee should consider, I would like to take this opportunity to call your attention to several other important Medicaid amendments that would go a long way in alleviating the burden of all disproportionate share hospitals. NAPH looks forward to an opportunity in the near future to describe the need for these amendments in greater detail, but we feel it is important to take this opportunity of our first appearance before you this year to list the following additional recommendations:

- The ability of states to make use of voluntary hospital contributions and provider-specific taxes as funding sources under Medicaid must be preserved and protected.
- A mandatory minimum adjustment for disproportionate share hospitals must be adopted, as should a mandatory minimum acceptable hospital payment rate overall.
- The right of States to pass through Medicaid payments for capital costs for disproportionate share hospitals, as has been adopted in California, must be preserved.

- Minimum adequate payment rates for hospital outpatient services, including a possible outpatient disproportionate share hospital adjustment, must be adopted.

- \* Eligibility and coverage for pregnant women and children must continue to be improved, including the elimination of state restrictions on days of care for these populations.

In closing, Mr. Chairman, I believe it is time to recognize that AIDS is now a mainstream issue for all Americans, and an all-consuming issue for public hospitals who treat the majority of the patients infected with this tragic disease. It was once necessary to distinguish AIDS from other health care issues in order to properly focus public attention on the gross deficiencies in our system for treating PWAs. However, now as we struggle to improve the treatment of AIDS, it is clear that we can no longer isolate the problems of confronting AIDS from the more general, and significant, problems posed for our health care system by the medically disenfranchised. We must therefore direct reforms, rendered urgent by the advent of AIDS and HIV infection, to the overall U.S. health care system, not merely to the disease itself.

Mr. WAXMAN. Mr. Conviser.

### STATEMENT OF RICHARD CONVISER

Mr. CONVISER. I am Richard Conviser, a consultant on AIDS policy and cost of care issues. I'd like to thank the subcommittee for the opportunity to address it today and particularly the chairman for the leadership he has shown in introducing legislation on additional Medicaid support for HIV. Today I am representing Children's Hospital of Newark, NJ, a private 129-bed tertiary care facility that serves both the State and its local community.

A recent study in New Jersey showed that about 200 children born each year will develop HIV infection. At Children's Hospital over half the infected children are born to mothers who use intravenous drugs and another third have mothers who are infected sexually.

The Children's Hospital AIDS Program, or CHAP, was formalized in 1984, and since that time it has cared for over 250 HIV-infected children. CHAP has a private foundation grant expiring this year that supports discharge planning personnel. They provide counseling, education, and family support, and they help children and their families gain access to community-based services.

New Jersey has a Medicaid waiver which provides reimbursement for the community-based services and about a quarter of the children seen at CHAP are enrolled in the waiver program.

The hospital is committed to family centered care. Because of its success in linking children with community-based services, only about 5 percent of the children in its AIDS program are hospitalized at any given time—they fill about 10 percent of the hospital's beds.

A 1987 survey of all AIDS hospitalizations in New Jersey show that the average admission for a child with AIDS costs nearly \$9,000 and lasted 2 weeks. Annual costs averaged over \$37,000 for an average of 61 days of hospitalization.

A study at Children's Hospital showed that after developing AIDS children averaged outpatient costs of over \$6,000 and inpatient costs of over \$47,000. If you add to this the cost of care before the children had developed AIDS, the effects of antiviral agents like AZT that prolongs survival and continuing coverage for those who were still alive at the study's end, the total cost of care comes to perhaps \$80,000 per child.

The vast majority of this cost is borne by Medicaid. At Children's Hospital over 85 percent of the infected children had Medicaid coverage and their care cost over \$10,000 more than that for children with private insurers.

This difference results from the greater severity of illness and multiple family problems of those with Medicaid coverage.

In other States, such problems often lead to prolonged inpatient admissions because there is no suitable place to send children to receive subacute care.

In New Jersey, the Medicaid waiver, a well developed foster care program and step-down facilities helped to reduce the incidence of medically unnecessary long hospital stays. Hospital reimbursement



in New Jersey is unusual, with a highly regulated, all payer diagnosis related group, that is DRG's system of prospective payment.

In 1986 and 1987, the State's hospitals lost about \$2,000 for every AIDS admission because payments were being made through DRGs developed prior to the onset of the epidemic. In 1989, New Jersey adopted 14 specific DRG's for HIV-related conditions, and these should ease the financial strain on hospitals.

New Jersey's 1987 statewide survey showed that avoidable long and short stays by HIV-infected children were most likely to occur in the hospitals that had the least experience.

As the HIV epidemic continues to spread and survival times lengthened from improved treatment protocols, the pressure on this country's health care system will continue to grow.

The fiscal consequences of that pressure, particularly for those hospitals with large numbers of Medicaid patients, could be serious unless there are upward adjustments in reimbursement rates.

The natural progression of HIV disease among already infected children will inevitably increase the need for inpatient care. But merely giving better reimbursement for acute care will not improve the quality of care for infected children.

The experience of Children's Hospital shows that case management contains costs and improves quality of care. But Children's will need support from Medicaid or other sources for case management when its private foundation grant funding dries up later this year.

Moreover, Medicaid coverage for community-based care needs to be made available to all HIV-infected children, not merely those who have already developed AIDS. Without it, a growing share of hospital resources will have to be devoted to the HIV epidemic. This would further compromise the ability of Children's Hospitals, particularly those located in inner cities, to provide care of the highest quality for all children in their communities.

Thank you.

[The prepared statement of Mr. Conviser follows:]

## Statement of

Richard Conviser, Ph.D., Consultant  
Children's Hospital AIDS Program  
Children's Hospital of New Jersey

I am Richard Conviser, a consultant on AIDS policy and cost of care issues. Since 1986 I have been doing research for the New Jersey State Department of Health, and in 1989 I worked with key staff members of the Children's Hospital AIDS Program at Children's Hospital of New Jersey and others to produce *Generations in Jeopardy*. This report from the New Jersey Pediatric AIDS Advisory Committee focuses upon the impact of the HIV epidemic on children, women, and adolescents. Currently I am collaborating on several pediatric AIDS research projects with the Children's Hospital AIDS Program, which I represent today. Mary Boland, the Program Director, is unable to be with you because she is hosting a site visit by the National Commission on AIDS.

Children's Hospital in Newark is a private 129-bed tertiary care facility and is the only specialty acute care hospital for children in New Jersey. Although about half of its admissions originate in referrals from throughout the state and region, Children's Hospital is also committed to providing primary and emergency care for the children who live in the surrounding urban community. These children comprise the other half of its patients.

A blinded seroprevalence survey of New Jersey's newborns in 1989 showed that one baby in 200 was born to an HIV-infected mother. Based on estimates that 30% of such babies will themselves become HIV-infected, at current rates New Jersey can expect about 200 babies born each year to develop HIV infection. Essex County, where Children's Hospital is located, is the epicenter of New Jersey's pediatric AIDS epidemic. For a baby born in Essex County, the odds of being HIV-infected are nearly three times as great as in the state as a whole.

Since 1984, when Children's Hospital formalized its AIDS Program (CHAP), the program has cared for over 250 HIV-infected children. Typically, such children occupy about 10% of the hospital's beds. Because of the program's capacity to link infected children with home- and community-based care, however, only about 5% of the children in the program are actually in the hospital at any given time. The discharge planning

personnel who help children and their families gain access to community-based services are supported by a private foundation grant that was awarded in 1986 and expires this year. Were it not for these services, and the Medicaid AIDS Community Care Alternatives Program (ACCAP) waiver that provides reimbursement for them, the HIV epidemic would place a far greater strain on the resources of Children's Hospital than it does. About 25% of the children seen at CHAP are enrolled in the ACCAP program, which reimburses for case management at the rate of \$100/month/child. All counseling, education, and family support at CHAP is funded through grant programs and is not currently Medicaid reimbursable. Unless funding is found to replace the expiring private foundation grant, Children's Hospital faces possible losses in discharge planning personnel, linkages with community-based services, and continuity of care.

A survey of all AIDS hospitalizations in New Jersey during 1987 showed that 69% (74/107) of the children on the state AIDS Registry were hospitalized during the year at nineteen acute care facilities. The average admission for an infected child cost over \$8,600 and was two weeks long. These per-admission averages are slightly below those for adults and adolescents (of over \$10,500 and 18.5 days per admission). However, children with AIDS typically had two or three hospital readmissions during the year--as opposed to an average of just one readmission for adults hospitalized with AIDS. Consequently, pediatric AIDS patients had significantly higher *annual* hospital use than their adult counterparts, averaging 61 days in the hospital during the year and over \$37,000 in hospital costs per child. Adult patients averaged just over 36 days and \$21,000. Twenty-one (28%) of the 74 children with AIDS hospitalized during the year died. The statewide survey showed that Children's Hospital cared for the largest number of pediatric AIDS cases in the state, accounting for one-third of all 1987 admissions.

We are just completing a study of inpatient and outpatient costs at Children's Hospital for the 155 HIV-infected children who received all their care there between 1984

and the end of 1988. Much of the care for children in the early stages of HIV illness is provided on an outpatient basis. Not surprisingly, however, as children become sicker, the locus of their care shifts increasingly to the inpatient ward. Patients with CDC-defined AIDS averaged outpatient costs of over \$6,000 and inpatient costs of over \$47,000 per child during the course of the study, for an average total cost of over \$53,000. However, this figure should be regarded as an underestimate of the average lifetime cost of care for children with AIDS. It does not take into account the cost of care prior to the development of AIDS, which averages nearly \$10,000. Neither does it show the effects of antiviral agents, such as AZT, that have been shown to prolong survival but had not yet been introduced to the pediatric population at the time of the study. In addition, over half of the children with AIDS enrolled in the Children's Hospital program were still living at the end of the study period, so the books on the cost of their care were not yet closed. An educated guess about the lifetime total cost of care for a child with AIDS would place it in the vicinity of \$75,000 to \$80,000.

In New Jersey, as in the other states with large numbers of pediatric AIDS cases, most of that cost is borne by Medicaid. The 1987 statewide survey of New Jersey AIDS hospitalizations showed that Medicaid was the primary payer for 79% of the children with AIDS and that private insurers--mainly Blue Cross--covered only about 12%. (About 8% were uninsured.) At Children's Hospital, the imbalance is even more extreme: over 85% of the HIV-infected children had Medicaid coverage, while private insurers covered just 9%. This contrasts with the 42% of all Children's Hospital patients (not just those with HIV) who have Medicaid as their primary payer, and the 40% covered by private payers.

Not only does Medicaid cover far more HIV-infected children than all other payers; these children also turn out to have higher inpatient costs than those with other payers. Both the statewide survey and Children's Hospital data estimate the difference in total costs between Medicaid- and privately-insured children to be in excess of \$10,000. It appears



that those covered by Medicaid are typically more severely ill than those with private payers. This may be an outgrowth of the limited access to health care (including prenatal care) of poor families in our society. In addition, the families of children with Medicaid coverage are likely to suffer from multiple problems.

At Children's Hospital, nearly 90% of the children seen by the AIDS program through 1988 had been infected perinatally. Over half (52%) of all the children had intravenous drug-using mothers, and the mothers of another one-third (36%) were infected by their sexual partners, who in most cases used intravenous drugs themselves. The lifestyle of drug-using parents seriously impairs their ability to care for their HIV-infected children. In addition, the birth of an HIV-infected child is often the first concrete evidence parents get that they are infected. This knowledge, along with the ravages of the disease, further compromises their ability to care for their infected children. Family disorganization, poor housing, and unsafe neighborhoods pose serious obstacles to providing community-based care to HIV-infected children, even where there is a Medicaid waiver program. In other states, Medicaid pays for many medically unnecessary acute hospital days accrued by sick infants requiring only subacute care who have nowhere else to go. New Jersey is fortunate in that it has the Medicaid waiver, a well-developed foster care program, and step-down facilities to treat such children. While these resources all minimize extended "social" admissions, unstable family situations sometimes still delay the discharge of children requiring continuing medical attention.

Concerns have been expressed in some quarters that designating particular hospitals as AIDS providers could encourage the development of a two-class system of care. In New Jersey, however, the hospitals that care for the greatest numbers of HIV-infected children have accounted for the least inappropriate utilization in the form of either very short or very long stays. It appears that these more experienced hospitals can improve the quality of care at other facilities by helping them to design treatment protocols. Toward this

end, the five highest-volume pediatric AIDS hospitals in New Jersey have been designated regional Pediatric HIV Treatment Centers through a Human Resources Services Administration (HRSA)-funded Pediatric AIDS Demonstration Project grant, and Children's Hospital has been designated a National Pediatric HIV Resource Center. All of these hospitals have multidisciplinary care teams that coordinate services with local providers.

Hospital reimbursement in New Jersey is highly regulated, and its all-payer Diagnosis-Related Group (DRG) system has been adjusted as a result of the HIV epidemic. However, an analysis of payments to the state's hospitals in 1986 and 1987--prior to the adjustment--showed that they were losing about \$2,000 for every AIDS-related admission. This occurred because AIDS patients require more care than others, and the DRG rates under which hospitals were being paid for their care were set before the growth of the epidemic. The adoption in 1989 of fourteen specific DRGs for HIV-related conditions should ease that financial strain; similar adjustments need to be made in other states and in federal programs. At Children's Hospital, the existence of funding to support patient care allows Pediatric AIDS Clinical Trials Group (ACTG) research funds, from the National Institute of Allergy and Infectious Diseases, to be used for research and not for patient care. The availability of investigational drugs for children through ACTG relieves third party payers of having to pay for them. These sources of support notwithstanding, the hospital faces the loss of a major private foundation grant for discharge planning activities that help to reduce the demand for inpatient services. Yet the epidemic shows no signs of slowing, and the natural progression of HIV disease among already-infected children will inevitably increase the need for inpatient care.

The continuing spread of the epidemic and lengthened survival times from improved treatment protocols will exert continuing pressure on the entire health care system. Without upward adjustments in reimbursement rates, the fiscal consequences of this pressure could threaten the survival of those hospitals that care for large numbers of Medicaid patients. But merely allowing hospitals to charge higher rates for acute care will not provide a lasting solution to improving the quality of care for infected children. Medicaid support is needed for the discharge planning activities that link children and their families with community-based services. We must improve access to these out-of-hospital services, for without them we cannot promote family-centered care. Adequate reimbursement must also be provided for nonmedical services, inside and outside the hospital. Should we fail to make such services available to HIV-infected children, a growing share of hospital resources will have to go to their care. This would further compromise the ability of children's hospitals, particularly those located in the inner city, to provide care of the highest quality for all children in their communities.

Mr. WAXMAN. Thank you very much, Mr. Conviser.

The three of you run hospitals and you do take Medicaid patients, and when you have an AIDS patient that's covered by Medicaid, let me just ask you this question for the record: Do you find that the Medicaid program in your State pays you less than the cost of caring for the individual with AIDS on an inpatient basis?

Ms. Loyd.

Ms. LOYD. Mr. Chairman, I'd like to respond to that.

Mr. WAXMAN. Let me ask you further, how much on the average you're losing on each patient if in fact you're not getting paid?

Ms. LOYD. On the average we're losing \$10,000. The average per admission per patient would be approximately \$14,000. Medicaid reimburses approximately 26 percent, which is about \$4,000, which leaves the hospital \$10,000, or better, to cover.

Mr. WAXMAN. How about you, Mr. Parrish?

Mr. PARRISH. Grady's experience is that the Medicaid reimbursement on a case-by-case basis covers 40 percent of the cost of hospitalization. It pays \$2,416 out of a \$5,982 cost for hospitalization. The difference between our figures and Jackson's is that Jackson has completed a renovation project which we are just beginning, so their numbers are a bit higher than ours for that reason.

I need to add, though, that the reimbursement in Georgia is an average of all Medicaid patients, so that the \$2,416 we get would be more than the cost of some hospitalizations and less than the cost of AIDS. So in the aggregate, with a 1-year lag, we are being paid for the cost of inpatient care for AIDS patients.

Mr. CONVISER. New Jersey has an all-payer system, and so the shortfall for Medicaid is the same for all of their payers. And as I mentioned in testimony, in 1987 there was about a \$2,000 per patient shortfall for AIDS patients. The State is redressing that by readjusting its reimbursement system with an interim payment to hospitals for patients up till 1989 and then the adoption of AIDS or HIV-specific diagnosis related groups beginning in 1989.

Mr. WAXMAN. A number of members of Congress, myself included, are interested in providing Federal assistance in the form of grants to States or localities to help out high incidence communities.

How do you think your hospital would do under this approach?

Would you prefer it to increasing the Medicaid reimbursements for patients with AIDS by 25 percent as proposed in the bill I introduced last week?

Ms. Loyd.

Ms. LOYD. Mr. Chairman, I feel that in fact it would be to our advantage to have the 25 percent increase in Medicaid because it would ensure that we were reimbursed for half of the reimbursement in terms of services that we are providing.

I feel that we are high incidence hospital and, therefore, we would benefit from the additional 25 percent increase in Medicaid.

Mr. WAXMAN. Mr. Parrish.

Mr. PARRISH. We would welcome the payment, Mr. Chairman. At the same time, we would favor even more a very aggressive incentive program to develop outpatient and community-based programs to try to alleviate some of the hospitalization that now goes on.

Mr. CONVISER. I'd like to mirror that for New Jersey. Given the particular circumstances of reimbursement what would help with the pediatric epidemic most would be substantially more support for out-of-hospital care.

Mr. WAXMAN. I know you don't want to choose, and I don't either, but let's say we're faced with the choice of either providing a higher reimbursement rate under Medicaid to hospitals for AIDS patients on the other hand, or emergency assistance for the communities that are hardest hit with the AIDS epidemic, which means that the communities could then distribute some of that money to the hospitals that are hard hit.

If you had to choose between the two, which one would you choose?

Ms. LOYD. Currently the State of Florida, Miami, we have a comprehensive outpatient component. We provide or reimburse all the providers at a Medicaid rate, whatever that Medicaid rate, through State appropriated dollars they are already reimbursed. The hospital is in fact probably the largest entity that's receiving less than they should in terms of compensation. So, therefore, I would support the 25 percent increase in Medicaid for the hospital.

Mr. WAXMAN. Mr. Parrish.

Mr. PARRISH. We would favor direct payment for patient care as contrasted with giving discretionary money to local communities.

Mr. WAXMAN. Mr. Conviser.

Mr. CONVISER. I would prefer to discuss this with the Director of the AIDS Program and I will respond later.

Mr. WAXMAN. We will be glad to receive that.

Following up on the previous question, one of the arguments against increasing Federal funds to public hospitals, whether indirectly through impact assistance block grants or directly through Medicaid, is that the locality will simply reduce its contribution to the hospital's operating budget by the amount of new Federal funds.

Do you think this argument is valid?

Ms. LOYD. The localities or local governments provide no additional dollars or funding for the South Florida AIDS Network so I don't think that that would have any impact.

Mr. WAXMAN. That's not a factor with you?

Ms. LOYD. No.

Mr. WAXMAN. Mr. Parrish.

Mr. PARRISH. I think it's a very valid concern and I certainly think there should be constraints built in that would preclude that. I don't believe that it would happen in Atlanta simply because of the relationship between the funding agencies and the hospital. I think there's a high degree of understanding of the need to deal effectively with AIDS and I would not anticipate local funding being withdrawn.

Mr. WAXMAN. Mr. Conviser.

Mr. CONVISER. In New Jersey, neither do I anticipate that localities would reduce their support.

Mr. WAXMAN. One of the arguments against the proposal I've introduced, increased Medicaid payments to hospitals serving high volumes of AIDS patients, is that it creates two classes of hospitals: one that serves AIDS patients and one that does not.



Do you think there's any merit to this argument?

Ms. LOYD. Considering Jackson Memorial provides the bulk of all services to AIDS patients in Dade County, we already have a two-class system. I don't foresee this enhancing that system any, but in fact it may entice or create an incentive for the hospitals to get involved.

Mr. WAXMAN. Mr. Parrish.

Mr. PARRISH. I think that Atlanta's record is a good one in terms of having the private hospitals and the public hospitals coordinate their activities in terms of everybody treating AIDS patients. All private hospitals in Atlanta treat AIDS patients, many private physicians do. And the working together and trying to maintain HIV infections is something that can be dealt with adequately in community hospitals and not just in specialized hospitals, I think is the approach we would prefer.

Mr. WAXMAN. Mr. Conviser.

Mr. CONVISER. In New Jersey, all hospitals care for adults and adolescents with AIDS. And as of 1987, 19 of the 87 acute care hospitals had already cared for children with AIDS.

In a sense, there could be an advantage to having hospitals that specialize in AIDS care. In New Jersey, in fact, five hospitals have been designated pediatric AIDS resource centers, and we found that those are hospitals that are most efficient in delivering low cost, high quality care to children.

The system being set up in New Jersey now is one whereby those regional resource centers are going to help other hospitals develop appropriate treatment protocols for children with AIDS.

Mr. WAXMAN. Thank you very much.

Mr. Dannemeyer.

Mr. DANNEMEYER. Thank you.

Ms. Loyd, I would like to ask what the current position of the Florida State Medical Society is on the issue of reportability for HIV carriers. Are you aware of what that position is?

Ms. LOYD. Yes, sir, I'm aware of that position.

Currently, they are developing a new policy in terms of HIV reportability. Currently, all AIDS patients, diagnosed patients who are full-blown AIDS are reportability—

Mr. DANNEMEYER. They haven't yet gotten to the point where they have adopted the recommendation of the American Medical Association, I take it, then?

Ms. LOYD. Sir, they do provide contact tracing through the county public health units in the State of Florida.

Mr. DANNEMEYER. Is the status of the current law in Florida such that you mandate when a physician encounters a patient who is an HIV carrier that that patient is reported to the public health authority?

Ms. LOYD. No, sir, that law is not in effect.

Mr. DANNEMEYER. Is there a suggestion in the State public health department that it be done?

Ms. LOYD. It's a suggestion, sir, but it's not a law.

Mr. DANNEMEYER. Do you favor it?

Ms. LOYD. Sir, I hold my opinion on that. I feel that with confidentiality there would be a lot of problems in trying to have a contact tracing policy.

Mr. DANNEMEYER. Can you give me one instance you mandate reportability of fully developed AIDS cases in Florida, don't you?

Ms. LOYD. Yes, sir, we do.

Mr. DANNEMEYER. And report it a little less than 10,000?

Ms. LOYD. Yes, sir.

Mr. DANNEMEYER. Can you give me one instance in the State of Florida where the identity of a fully developed AIDS patient has been revealed from public health authorities to persons not authorized to know it?

Ms. LOYD. Sir, I don't know of one.

Mr. DANNEMEYER. I don't either.

Mr. PARRISH, how about the State of Georgia, what's the status of the medical association in the State of Georgia, have they yet implemented the recommendation of the American Medical Association in reportability for HIV carriers?

Mr. PARRISH. I'll be glad to try to get an answer to that question, Mr. Dannemeyer, I'm just speaking for the providers of health care. I'm not speaking as a public health policy official at all.

Mr. DANNEMEYER. But you have some contact with medical people in the State of Georgia, don't you?

Do you know what the current status of the law is in the State of Georgia on the issue of reportability for HIV carriers?

Mr. PARRISH. The practice, as far as I am aware, is the one that was described by Dr. Koop earlier.

Mr. DANNEMEYER. If you don't know, just tell me, that's okay. But if you do know what the current policy of the State law in Georgia is, I'd appreciate it if you would tell me that, if you know it.

Mr. PARRISH. AIDS cases are reportable.

Mr. DANNEMEYER. How much HIV carriers, are they reported?

Mr. PARRISH. I do not know.

Mr. DANNEMEYER. All right.

I noticed that in the State of Georgia—did I understand you to say that 56 percent of the AIDS cases are not covered by Medicaid?

Mr. PARRISH. In our hospital, 50 percent of the patients that have HIV infections—56 percent of the patients for whom we're treating HIV infections have no coverage of any sort.

Mr. DANNEMEYER. But according to the law in the State of Georgia, a family of two, if they earn \$220 a month, then they would not be eligible for Medicaid by State law, correct?

Mr. PARRISH. I don't know the numbers exactly. It's a very low number, which is being revised.

Mr. DANNEMEYER. Obviously, the State of Georgia would raise that level of earnings to establish eligibility, then that would increase the percentage of patients in Georgia that would be treated with AIDS, wouldn't it?

Mr. PARRISH. Yes, sir, it would, and we support that.

Mr. DANNEMEYER. Mr. Conviser, I understand in the State of New Jersey, you've recently adopted a law mandating reportability for HIV carriers; is that right?

Mr. CONVISER. I know that such a law is up for consideration—I'm not aware that it has been adopted yet.

Mr. DANNEMEYER. It has been my intelligence that New Jersey has adopted a dual system whereby it mandates reportability for

HIV carriers but has established anonymous testing centers where persons who can go there and they are tested in the anonymous testing center, then they know there will be no reportability from them.

Mr. CONVISER. I don't know about the relationship between the two. I do know that the anonymous testing centers have been in place for several years in New Jersey.

Mr. DANNEMEYER. One of the problems we have from public policy, and this question is directed to all three of the members of the panel, and it was also directed to Dr. Koop, and I think it's obvious to all of us, is that from the standpoint of Federal policy, we will expend Federal tax dollars to Medicaid eligible people provided they can pass a means test. But in this instance the proposal by Mr. Waxman is that we would make an exception for AIDS carriers and because of the magnitude of the problem.

Mr. WAXMAN. If the gentleman will yield to me, that's not correct.

What we're proposing, that they still meet the same economic test to be eligible but not have to be disabled, which is another test in addition.

For example, Mr. Parrish talked about Medicaid paying more if the level were raised. On the other hand, if they're not disabled they still wouldn't get Medicaid. So we are saying for the purpose of early intervention drugs that if they meet the economic test they also would be eligible for Medicaid for the payment of those drugs.

Mr. DANNEMEYER. Even though they haven't met the disabled test?

Mr. WAXMAN. They wouldn't meet the disabled test because they only have the infection and they won't be disabled until they get AIDS.

Mr. DANNEMEYER. But the public policy question we have is, you know, we have a lot of people afflicted with heart disease and cancer and other debilitating illnesses in the country who would not be treated on the same basis. How do we justify treating AIDS patients differently than how we've dealt with these other diseases that are killers in America?

That's the public policy question.

Mr. WAXMAN. The difference is that these patients are going to be patients for whom we are going to clearly pay the cost for their health care hospitalization because we are not preventing the AIDS from developing from the infection. With the others we have no way to prevent heart attacks or cancer from an early position. If we did, we would certainly want to intervene. But we do have a way to stop, when someone's infected, them from developing full-blown AIDS. To withhold health care until they get full-blown AIDS means we're going to pay up more money for them for the hospitalization as well as forcing people to be disabled.

Mr. DANNEMEYER. We can argue that, I guess, at length.

I guess my time has expired now. I'll have another round, perhaps, Mr. Chairman.

Mr. WAXMAN. Mr. Scheuer.

Mr. SCHEUER. Mr. Conviser, I was intrigued by your reference to pediatric hospitals in New York that are now specializing. I think you called them pediatric resource centers or something of the



kind—that are now specializing and offering low-cost, high quality care to these kids.

I think we are all desperately looking for some way to find a lower cost, high quality care model for AIDS patients, avoiding the disruption of emergency rooms in hospitals, which is a bizarre way to treat AIDS people—avoiding using hospital rooms in a building with all kinds of pipes and electric wires in incredibly high-tech facilities are costing hundreds and hundreds of dollars per square foot—when many of these patients, if not most of them, could be attended in much, much simpler buildings at far lower cost.

So what I would like you to do—and any of the others please chime in—is elaborate on what are some of the approaches you use that do reduce costs while maintaining reasonable quality.

Mr. CONVISER. There are two kinds of avoidable hospital admissions for children with AIDS, very short stays for procedures that could be done on an outpatient basis and very long stays that are a consequence of the social circumstances of the child's family rather than medical necessity. And there's an interplay between the social circumstances and medical necessity; a child who has received acute care can be discharged into the care of alert parents or other facilities, the child will need continuing medical attention but doesn't need the level of medical attention provided in hospitals.

So good discharge planning, case management programs, can see to it that children receive the care at the facility that is most appropriate to their need instead of the children automatically going to acute care hospitals for all of their needs.

Let me add, however, that with children infected with AIDS, since most of them are from families of intravenous drug users—either mother or father, or both—and because the news that a child is HIV-infected may often be the first evidence that the parent has of his or her own HIV infection oftentimes is very complicated to discharge children to the care of their families.

Extended families sometimes come into the breach. A network of step-down facilities such as the ones in New Jersey is developing help where there may be five or six beds in the facility under close supervision of physicians and nurses—far less costly than acute care hospitals. And these step-down facilities also serve as a recruiting ground for foster parents. And New Jersey has been very fortunate in being able to discharge HIV-infected children to foster parents who are willing to look after them.

Mr. SCHEUER. What kind of a structure would it be that has facilities for five or six beds? Is that a private house?

Mr. CONVISER. Generally, yes.

There are several such structures are converted private houses in New Jersey now.

Mr. SCHEUER. So you could take a private house, and I guess for most of the day the care would be under a paraprofessional, a semi-professional, other than a professional person, with doctor and professional nursing supervision from time to time?

Mr. CONVISER. Correct.

Mr. SCHEUER. Has this been written up in New Jersey? Has this been codified?

Mr. CONVISER. Yes, it has been, and we have published in the journal AIDS and Public Policy about this of kind of arrangement.



Mr. SCHEUER. I would like to ask unanimous consent that we get a copy of whatever you have to offer that would give other cities and States guidance on how they can develop modalities for lesser cost, high quality care.

I think this is what we're all thirsting for. We are appalled at the burden of AIDS, as I say, sopping up urgently needed moneys for other elements in the health care system—preventive health care, prenatal, postnatal—preventing us from addressing the needs of 31 million Americans who don't have access to the health care system.

I have to balance other needs, very compelling needs, outside of the health care system, and I just took Head Start as one example. We have a couple of million kids in this country who ought to be in Head Start. Yet, we're only funding one in six of the Head Start slots that should be available to kids in urgent education risk.

Now President Bush's proposal for this year would reduce that unmet need from one in six to one in five. But even under President Bush's proposal to add another \$500 million to Head Start, still we would consigning 80 percent of the kids at education risk to almost certain, predictable education failure.

So this looming burden of \$10 to \$15 billion in the next 3 or 4 years of AIDS is a terrible burden on our society, not only within the technology, but for other competing needs of society—and I just take education as one urgently pressing need.

So your quest and your mission of finding a lower cost but nevertheless high quality health care modality for both kids and adults is absolutely quintessentially important.

Mr. CONVISER. If I might follow up with a small point germane to the bill under consideration, as I mentioned briefly in my testimony, I feel that the bill could fruitfully be amended to extend Medicaid coverage out of hospital to children who are HIV-infected. The language of the bill right now would limit that care to children who have already developed AIDS. Children who have already developed AIDS generally need a lot of inpatient care no matter how much we do to buttress the other elements of the system.

So I would like to see the bill amended to extend that kind of coverage to all children with confirmed HIV infection.

Mr. PARRISH. Mr. Chairman, may I add a response to Mr. Scheuer's question?

Mr. WAXMAN. Yes.

Mr. PARRISH. All three of the hospitals represented here have alternative programs to hospitalization. We all have a continuum of care. Richard's hospital and mine and Barbara's are all involved in these and they do paraprofessionals to provide a much less expensive, albeit much more acceptable to the patient, much higher quality care than you can provide in a bed. We've all recognized that none of us want to be in a bed when there's a decent alternative. I think all three of these hospitals and many other public hospitals around the country have in fact done a great deal in that regard.

It's just that in spite of all that, we are now having to hospitalize some patients, and the cost of paying for those hospitalizations and the number of beds they take up that just aren't there is what's overwhelming the public hospitals.

We are using the community resources, I think, very effectively.

Mr. WAXMAN. Thank you, Mr. Scheuer.

Mr. SCHEUER. Thank you, Mr. Chairman.

Mr. WAXMAN. Mr. Nielson.

Mr. NIELSON. Mr. Parrish, you mentioned in your testimony that the length of stay at public hospitals in the northeast is much longer than any other region in the country.

Why is that the case?

Mr. Parrish.

Mr. PARRISH. I didn't mention that.

Mr. NIELSON. It's in your testimony.

Mr. PARRISH. I'm sorry, you're right, it's in what was submitted for the record.

Mr. NIELSON. Yes, it's in the record, that's where it is, okay.

Why is it so much higher in the northeast?

Mr. PARRISH. I'm not prepared to address that. I'd be glad to have the association get that answer for the record.

Mr. NIELSON. Does that have anything to do with the fact that there are a larger number of drug abusers in the northeast or not?

Mr. CONVISER. If I may speak to that.

Mr. NIELSON. I'd rather have Mr. Parrish; he's the one that made the statement, and then I'll call upon you.

Mr. PARRISH. There is a larger incidence of drug abuse there than what we've experienced. And the presumption would have to be that that is correct.

Mr. NIELSON. Mr. Conviser, would you like to add to that?

Mr. CONVISER. There have always been variations in the length of time people spend in hospitals in different regions of the country for all diagnoses. The West Coast has a tradition of being quite expensive but getting patients out quickly. The East Coast has a tradition of being less costly per day but keeping patients in for a longer period of time.

Mr. NIELSON. Thank you.

Mr. Parrish, would you care to guess what percentage the total cost of AIDS care is reimbursed? I mean to include those you have to pay the entire cost of and those you pay a partial cost of.

Mr. PARRISH. Do you mean at my hospital?

Mr. NIELSON. Yes, in your hospital.

Mr. PARRISH. About 20 to 30 percent is reimbursed by Medicaid.

Mr. NIELSON. That's of those who are under Medicaid.

What about those who come in with no hospitalization of any kind? Don't you pick up some of those as well?

Mr. PARRISH. Fifty-six percent of all the care that we give for AIDS patients is not reimbursed by any third-party payer.

Mr. NIELSON. So you pay the entire cost for the 56 percent and 80 percent of the cost for the balance, would that be something like that?

Mr. PARRISH. On outpatients it's not 80 percent; the Medicaid program would tend to cover 100 percent of that.

Mr. NIELSON. I see. I wish you'd kind of put your weighted average on to give us some overall figure on that one.

On page 11 of your testimony you mentioned the public hospital losses for inpatient services are \$218 per day but that the losses for outpatients was \$264. That seems rather strange to me that the loss for an outpatient is more than the loss for an inpatient.



Do you have an explanation for that?

Mr. PARRISH. I can give you a partial explanation. There are some States that have a cap on what Medicaid will pay for an outpatient visit. An outpatient visit in our hospital is a complicated visit in that it involves expensive kinds of diagnostic therapy such as bronchoscopies and x-ray studies that are done in order to avoid a more expensive hospitalization. So you might find a clinic visit costing several hundred dollars.

In some States there's a Medicaid cap of \$60, for example, on clinic visits, so that doesn't provide much of an incentive for those States to do care on an ambulatory basis when they are reimbursed at a higher rate if the patient is an inpatient.

Mr. NIELSON. On that page 11 you're talking about these figures. Are you referring to all patients or just the HIV AIDS patients? Paragraph No. 1, page 11, of your testimony.

Does that refer to all patients or just AIDS and HIV patients?

And if it's just AIDS and HIV, will H.R. 4080 impact these losses at all?

Mr. PARRISH. This is AIDS.

Mr. NIELSON. Just AIDS.

How will H.R. 4080 help in this regard? How will it impact it?

Mr. PARRISH. I think a major way that it will help is encouraging more outpatient initiatives.

Mr. NIELSON. Even though you lose more on that process?

Mr. PARRISH. You mean lose more on——

Mr. NIELSON. Per day, per patient.

Mr. PARRISH. We would be looking for——

Mr. NIELSON. That's a very philanthropic point of view—you would rather have more of the kind you lose more on than the ones you would lose less on.

Mr. PARRISH. My concern is that if the reimbursement rates are significantly better on inpatients, we will tend to develop more inpatient programs.

Mr. NIELSON. So we should do a better job of reimbursing properly, then, is what you're saying?

Mr. PARRISH. I think the reimbursement should be slanted to reimburse for the most effective kind of care and not to presume that that's inpatient.

Mr. NIELSON. Which, in your case, is outpatient because you can do more and get them out faster and more effective use of your time, right?

Mr. PARRISH. We believe that's a better use of the dollars and it's a better use of the patient's time, that it's a higher quality of life for the individuals involved.

Mr. NIELSON. Do you have special problems financing hospital service for AIDS patients in the south primarily to Medicaid eligibility requirements?

Mr. PARRISH. Yes, sir, we do.

Mr. NIELSON. Would H.R. 4080 help remedy this problem as well?

Mr. PARRISH. Yes, sir, it would help.

Mr. NIELSON. You mentioned that 30 percent of the AIDS patients at Grady could be more appropriately cared for in either skilled or custodial nursing home beds.

Is this typical of all hospitals in your region?

Mr. PARRISH. All hospitals where?

Mr. NIELSON. All hospitals in your region who serve a large number of AIDS victims.

Mr. PARRISH. Some States have nursing homes that will accept AIDS patients. Georgia is not one of them.

Mr. NIELSON. If I may continue this and this is the last question.

If these patients were moved to such facilities, that is, skilled or custodial nursing cares, would that alleviate the financial burden on the hospitals?

Mr. PARRISH. It might just mean that another AIDS patient would take that bed. But in terms of looking after the total number of people that the epidemic is affecting, yes, it lowers the cost, because the cost of a nursing home is less than the cost of a hospital bed.

Mr. NIELSON. Mr. Chairman, will we have another round?

Mr. WAXMAN. If members wish another round.

Mr. NIELSON. If not, I have a whole series of questions for Mr. Conviser I didn't get to, either him or Ms. Loyd.

Mr. WAXMAN. I would prefer we not have another round because we're running late.

Mr. NIELSON. All right, I would like to submit these for the record.

Mr. WAXMAN. That's fine if the gentleman's willing to do that. Dr. Rowland.

Mr. ROWLAND. Thank you, Mr. Chairman.

I express my thanks to each of you for coming, and especially to the fellow Georgian, Robert Parrish, for being here, and I wish to direct my question to him and to the other two if it's appropriate.

I'm told by the administrator of the hospital in Macon, GA that at any one time he has one or more AIDS patients from the rural area of the State—outside of Bibb County, which is the county seat of that county.

What has been your experience with AIDS patients outside of the metropolitan Atlanta area during the last couple of years?

Mr. PARRISH. We've had about 85 percent of our patients coming from Fulton County into DeKalb County, with the remainder primarily from the rest of the State—and an occasional individual who's outside the State.

We do get some State money for the clinic that we operate, and so a condition of that State money was that we would take some patients for outpatient care from other parts of the State, and we do that.

Mr. ROWLAND. Has there been any change in the last, say, 2 years, number of patients from the rural areas versus the number that you have from the metropolitan area?

Mr. PARRISH. Yes, sir, there's been an increase. You mentioned earlier that the increases in central Georgia are very dramatic. In terms of absolute numbers, they don't compare to metropolitan Atlanta. But in testimony to the Georgia legislature 2 weeks ago, Dr. Wilber, from the State Health Department, said that he advises people with HIV problems to come to Atlanta when they are not near a population center that provides support.

So with that kind of concrete advice coming from the State Health Department, we are seeing increases in those numbers.



Mr. ROWLAND. Would it be appropriate for either of you to answer that question relative to the rural areas of your States?

Ms. LOYD. In Florida each one of the surrounding counties, which would be Monroe County, Broward County, and Palm Beach County, they all have networks and they all are a part of the South Florida AIDS Network. The South Florida AIDS Network basically has the highest incident of AIDS in the State. So the accumulative totals for the State would be about 4,000 to 5,000 patients, which is half of the State's actual reportable cases. So we don't have the same problems. Each one of the surrounding counties are able to provide the adequate services and provide the needed followup to the patients in their particular areas.

Mr. CONVISER. In terms of New Jersey, to speak specifically about pediatric AIDS, a survey has shown babies are being born HIV-infected all over the State. This is a change from a number of years ago when the epidemic was largely confined to the northeastern urban area of the State.

Mr. ROWLAND. So you're getting some from the rural areas of New Jersey also?

Mr. CONVISER. That's correct.

Mr. ROWLAND. Let me ask a question about what happens to an individual, Mr. Parrish, who is able to leave the hospital, who has AIDS but does not have any place to go and is not financially able to take care of themselves?

Mr. PARRISH. That's a complicated issue, Dr. Rowland. It's probably the most difficult one we deal with on a daily basis. There's some beginning programs such as Jerusalem House for Adults and Child Kind for Babies where somebody with no family support can enter a custodial type of residential care.

But that's still a significant unmet need in Atlanta and it's separate from the availability or nonavailability of nursing homes; it's just a need for supportive living for people who can still maintain a residential lifestyle if they have some support.

Mr. ROWLAND. It's a very difficult problem to deal with and one that we have not dealt with very well at this point.

Mr. Dannemeyer had asked about Georgia; I am familiar with Georgia. Are you interested in me giving that to you or do you want to just let me provide it for you later? They're about what Georgia does, with reference to reporting. You asked a question, Mr. Dannemeyer.

Mr. DANNEMEYER. Right. What's Florida done?

Mr. ROWLAND. No, I'm talking about Georgia.

Mr. DANNEMEYER. Georgia?

Mr. ROWLAND. Yes.

Mr. DANNEMEYER. What's the current status of the law of Georgia on that.

Mr. ROWLAND. There are two ways to report in Georgia: One is confidential, in which the name of the individual is retained in the medical record and it is reported demographically to the Department of Human Resources. The other is anonymous testing where the name is not retained but the information is reported demographically to the Department of Human Resources.

In view of the fact that the disease seems to be becoming more chronic now with the use of AZT in seropositive people, that seems to be working very well at this point.

Mr. DANNEMEYER. Will the gentleman yield for a question?

Mr. ROWLAND. Sure.

Mr. DANNEMEYER. How can you conduct contact tracing with anonymous reportability?

Mr. ROWLAND. I'm not talking about contact tracing. I'm talking about reporting from the standpoint of people getting tested for the disease.

Mr. DANNEMEYER. Thank you.

Mr. WAXMAN. Thank you, Dr. Rowland.

Mr. Towns.

Mr. TOWNS. Thank you very much, Mr. Chairman, for holding this hearing.

I was detained at the beginning of the hearing and ask that my opening statement be placed in the record.

Mr. WAXMAN. Without objection, the gentleman's opening statement will be placed in the record at the appropriate spot. [See p. 24.]

Mr. TOWNS. Thank you.

I guess this would probably be for you, Ms. Loyd, and for you, Mr. Parrish. Are patients in your various hospitals denied access to AZT and other therapies because these therapies aren't covered by Medicaid?

Ms. LOYD. In Miami, or the State of Florida, through the State Health Office, all clients who are Medicaid-eligible can receive AZT through that particular entity. The clients who are not covered under the Medicaid waiver provision, the hospital assumes the cost and we continue to provide that.

In addition to that, through the University of Miami, a special drug protocol exists in AZT and other experimental drugs are provided to patients as they are identified for that drug.

Mr. TOWNS. Mr. Parrish.

Mr. PARRISH. In the Grady situation, AZT and phentaminine are both approved drugs for the hospital, which means that regardless of the patient's financial status or who is paying for it, if the right level of physician prescribes the drug then it will be delivered.

The problem with that is that it's producing a strain on the financial resources of the hospital in terms of adding that to the expense of the budget when you don't have any offsetting revenue to pay for it.

Mr. TOWNS. Could you give me a percentage of those who would fall into the category of being denied access to the drug because of the impact on the budget?

Mr. PARRISH. We don't deny the drugs to anyone. If there's a patient who is being treated in our clinic who requires the opinion of the physician who is directing the care, either pentaminine or AZT, then the patient gets that drug.

I'm just saying that it produces budget overages that have to be made up by the local tax base, which is getting increasingly difficult.

Mr. TOWNS. Let me put it this way then: Forty percent of all the AIDS patients qualify for Medicaid. I know you said 30 but nation-

ally about 40 percent, we would say, qualify. There are about 60,000 living AIDS patients in the Nation. And, there are about 510,000 Americans with HIV infections whose immune system is low enough to need AZT.

What percent of these would you say that are getting it?

Mr. PARRISH. That's a matter of discretion with individual physicians in dealing with their patients in different parts of the country, and there's some diversity in medical opinions about who gets AZT and who doesn't.

I can just tell you that in my own situation when the infectious disease physicians believe that it would be effective in staving off the PCP or other life-threatening problems then the patients do in fact receive it.

The problem is not whether the patient gets it or not; the problem is who pays for it, in our situation.

Mr. TOWNS. Do health plans provided by unions cover it, or does a third party?

Mr. PARRISH. You mean trade union insurance policy?

Mr. TOWNS. Yes, right.

Mr. PARRISH. Most of those patients would be going to private hospitals in Atlanta and would not be coming to a public hospital. As far as I know we don't have any union members who are in our AIDS clinic.

Mr. TOWNS. Ms. Loyd.

Ms. LOYD. My population is also the indigent population or borderline indigent population. Patients who are able to pay for their own therapies are not in my system and, therefore, I could not respond to that.

Mr. TOWNS. Thank you very much.

Mr. Chairman, I have no further questions. I yield back the balance of my time.

Mr. WAXMAN. Thank you very much, Mr. Towns.

We want to thank the three of you for your response to the questions and for your testimony. We would like you to respond to additional questions that members may have which will be submitted to you in writing and we'd like your responses in writing for the record.

Thank you very much.

Mr. PARRISH. Thank you.

Mr. WAXMAN. Our next panelist is Kenneth Thorpe, a health economist at Harvard School of Public Health. Mr. Thorpe is currently serving as a consultant to the Pepper Commission on Comprehensive Health Care, helping the commissioners, including myself, understand the costs of reforming Medicaid and of developing an alternative public program.

We've asked Mr. Thorpe to take on a particularly difficult task this morning to discuss the economic impact of the HIV epidemic on the Medicaid program over the next few years.

The basic reason this is so difficult is the uncertainty about the scope of the HIV epidemic and its rate of growth. I want you to know that I greatly appreciate your willingness on short notice to help the subcommittee get a better sense of the epidemic's costs.

We're pleased that you're here. Your prepared statement will be made part of the record in full. We'd like to ask, if you would, to



limit your oral presentation to no more than 5 minutes so we can have questions and answers.

**STATEMENT OF KENNETH E. THORPE, DIRECTOR, PROGRAM ON HEALTH CARE FINANCING AND INSURANCE, DEPARTMENT OF HEALTH POLICY AND MANAGEMENT, HARVARD UNIVERSITY SCHOOL OF PUBLIC HEALTH**

Mr. THORPE. Thank you, Mr. Chairman, members of the committee, my name is Kenneth Thorpe. I am director of the program on health care financing at Harvard University School of Public Health.

The focus of my testimony today is to document the expected growth in Medicaid financing of medical care costs resulting from AIDS. Like the underlying estimates of new AIDS cases, changing treatment patterns and changes in survival probabilities, substantial uncertainty underlie these estimates.

My discussion today will focus on three major areas. First, the growth in the number of AIDS cases; second, the medical costs of treating AIDS patients; and, finally, the implication of these trends in the Medicaid program.

With respect to those points, I'd like to make six major points.

First, just for visual effects, if not for ease of presentation, I've brought some charts to examine.

[Charts shown.]

Mr. THORPE. My first point is that the expected number of new AIDS cases will rise at least through 1993. Although the increase in reported AIDS cases slowed in 1987, data recently released by the Centers for Disease Control indicate the expected number of new AIDS cases will increase 46 percent between 1990 and 1993.

I should hasten to say that these are the latest estimates that I've been able to get a hold of. They represent the results from a Consensus Panel on HIV Modeling, which was held in November, where all the leading mathematical models of the epidemic were convened. And I think it represents the latest in the technology, at least that I've seen, on changes in the number of AIDS cases. So the first point is the number of cases are going to rise substantially.

The second point is that given the increases in survival probabilities, the number of persons living with AIDS during the year is going to increase 70 percent between 1990 and 1993. The distribution of existing new cases of AIDS will remain disproportionately located in eight States. As of 1990, eight States accounted for approximately 72 percent of all new AIDS cases.

We've talked a lot about them this morning—New York and California being the leading States. However, Florida, Texas, New Jersey, are also rapidly catching up with New York and California.

The third point that I want to make is that relative to other types of major health care expenditures, Medicaid finances a substantial portion of AIDS care. Nationally, as you can see from the chart, Medicaid extends coverage to approximately 9 percent of all Americans. In addition, the most recent data from the Current Population Survey indicate that 32.7 million, some 13 percent of all Americans, are currently uninsured.



In contrast, however, Medicaid covers an estimated 40 to 45 percent of all AIDS patients, with another 20 percent of AIDS patients uninsured. The high percentage of AIDS patients covered by Medicaid results from a combination of the socioeconomic status of the population at risk and changes in policy making it easier to qualify for coverage on the basis of disability. However, Medicaid coverage of AIDS patients varies widely across States. The percent of persons with AIDS eligible for Medicaid ranges from a low of 10 percent in Texas to nearly 70 percent in New York State.

The fourth point is that AIDS patients are treated in few hospitals which incur substantial financial losses.

A 1987 survey of hospitals indicates fewer than 5 percent of hospitals treat approximately half of all AIDS cases. Nationally, using some other estimates, I've estimated that the Medicaid program in general pays hospitals approximately \$3 to \$4 billion below costs.

If you look at the results from the AIDS survey, which was published, hospitals typically—nationally, that is—hospitals typically incur losses of approximately \$1,000 to \$5,000 per AIDS patients.

The fifth point is costs of treating persons with AIDS are high and likely to continue to escalate.

Recent studies indicate that the yearly Medicaid costs of treating persons with AIDS ranges from \$25,000 to \$60,000 per year. This range still places Medicaid costs of treating persons with AIDS among the highest of all Medicaid services—only nursing home expenditures, averaging approximately \$30,000 per recipient, is close to the AIDS figure.

The sixth point, if we can get to that next chart—based on some projections that I've just made using the latest CDC data, persons with AIDS for the Medicaid budget, as of 1990 will incur approximately \$1.6 billion worth of Medicaid expenditures.

This represents approximately 4.2 percent of all Medicaid spending on the nonelderly and 2.7 percent of the total Medicaid budget.

If you look at the projections I've made through 1993, you'll see that the expenditures for AIDS under the Medicaid program is going to triple, rising by 1993 to approximately \$3.7 billion.

Finally, if you will look at the last chart, you'll see that AIDS, if you pull out nursing home expenditures, in 1989 is going to account for approximately 3.7 percent of Medicaid spending; by 1993, something over 7 percent of all Medicaid expenditures.

Mr. WAXMAN. Thank you very much, Mr. Thorpe. I want to proceed to questions if I might.

[Testimony resumes on p. 102.]

[The prepared statement of Mr. Thorpe follows:]

STATEMENT OF KENNETH E. THORPE, DIRECTOR, PROGRAM ON HEALTH CARE FINANCING AND INSURANCE, HARVARD UNIVERSITY SCHOOL OF PUBLIC HEALTH

Mr. Chairman, members of the Committee, my name is Kenneth E. Thorpe. I am Director of the Program on Health Care Financing and Insurance in the Department of Health Policy and Management, Harvard University School of Public Health. I am also affiliated with the Harvard AIDS Institute.

The focus of my testimony is to document the expected growth in Medicaid financing of medical care costs resulting from the acquired immune deficiency syndrome (AIDS). Like the underlying estimates of new AIDS cases, changing treatment patterns, and changes in survival probabilities, substantial uncertainty underlie these estimates. Hence, the results of my survey of the literature do not provide exact numbers, but rather represent point estimates with little precision. The discussion presented below focuses on three major areas: first, the epidemiology of AIDS, second, the medical costs of treating AIDS patients and finally the implications of these trends on the Medicaid program. The results show:

1. THE EXPECTED NUMBER OF NEW AIDS CASES WILL RISE THROUGH 1993.

(see Figures 1 and 2)

Although the rate of increase in reported AIDS cases slowed during 1987, data recently released by the Centers for Disease Control (CDC) indicate the expected number of new AIDS cases will increase 46 percent between 1990 and 1993. In addition, increases in the one-year survival rates among those with *Pneumocystis carinii* Pneumonia (PCP) has resulted in a substantial increase in the number of AIDS patients alive during the year. The CDC estimates, resulting from their October, 1989 HIV/AIDS mathematical modelling workshop, indicate that persons alive with AIDS during the year will increase nearly 70 percent between 1990 and 1993. Thus, while the rate of increase appears lower than previously estimated, the number of AIDS cases will continue to increase across each of its transmission categories (i.e. IVDU, homosexual/bisexual men, children and heterosexual transmission).

2. THE DISTRIBUTION OF EXISTING AND NEW CASES OF AIDS WILL REMAIN DISPROPORTIONATELY LOCATED IN 8 STATES.

(see Figure 3)

As of 1989, 8 states accounted for 71.6 percent of new AIDS cases. New York and California have the highest number of new cases (19.1 and 18.7 percent respectively) with Florida, Texas and New Jersey each having at least 6.9 percent of the national total. Regionally, the number of AIDS cases in the northeast is greatest (34 percent), followed by the south (31 percent), west (24 percent) and the central region (10).

### 3. RELATIVE TO OTHER MAJOR SPENDING, MEDICAID FINANCES A SUBSTANTIAL PORTION OF AIDS MEDICAL EXPENDITURES.

(see Figure 4)

Nationally, the Medicaid program extends coverage to 9 percent of all Americans. In addition, the most recent data from the Current Population Survey (CPS) indicate that 32.7 million, some 13 percent, of all Americans are currently uninsured. In contrast, Medicaid covers an estimated 40 to 45 percent of all AIDS patients, with another 20 percent of AIDS patients uninsured. The high percentage of AIDS patients covered by Medicaid results from a combination of the socioeconomic status of the population at risk and changes in policy making it easier to qualify for coverage on the basis of disability. However, Medicaid coverage of AIDS patients varies widely across states. The percent of persons with AIDS eligible for Medicaid ranges from a low of 10 percent in Texas to nearly 70 percent in New York State. Recent expansions of the Medicaid program, combined with longer survival times among AIDS patients (thus increasing the number of individuals receiving Medicaid through the medically needy option) is likely to increase the share of AIDS patients receiving care through the Medicaid program.

Medicaid is the payor of last resort for individuals with AIDS. Persons with AIDS (PWA) may become eligible for Medicaid through the Federal Supplemental Security Income (SSI) program. Persons with AIDS meet the definition of disability. Assuming they meet the income and asset thresholds of the SSI program, PWAs would become eligible for Medicaid in most states. Those with incomes or assets which exceed the AFDC or SSI thresholds may, in 36 states, eventually become eligible under state "medically needy" provisions.

### 4. AIDS PATIENTS ARE TREATED IN FEW HOSPITALS WHICH INCUR SUBSTANTIAL FINANCIAL LOSSES

(see Figures 5 and 6)

A 1987 AIDS survey of hospitals completed by Andrulis and colleagues indicated that fewer than 5 percent of hospitals treat approximately 50 percent of all AIDS patients. Nationally, I have estimated elsewhere that Medicaid reimburses hospitals at approximately 80 percent of reported costs. This translates into Medicaid payments of \$3 to \$4 billion below reported hospital costs. For many of the large public and academic medical centers in urban areas, losses associated with treating AIDS patients (as a proportion of costs) are even higher. The 1987 AIDS survey indicated that hospitals typically incurred costs \$1,000 to \$5,000 more than revenues.

**5. COSTS OF TREATING PERSONS WITH AIDS ARE HIGH AND LIKELY WILL CONTINUE TO ESCALATE.**

(see Figure 5)

Recent studies indicate that yearly Medicaid costs of treating PWAs ranges from \$25,000 to \$60,000. This range reflects substantial differences across states in the scope of services provided under the Medicaid program as well as reimbursement rates. This range still places the Medicaid costs of treating PWAs among the highest of all Medicaid services. Only Medicaid nursing home expenditures, averaging around \$30,000 per recipient, is close to the AIDS figure. Projecting the future costs of treating AIDS patients is complicated for a number of reasons. First, treatment patterns are rapidly changing and perhaps as a result so are changes in the length of patients' survival time. The introduction of AZT, for instance, has facilitated the treatment of many patients on an ambulatory basis. A growing literature has indicated that AZT and anti-PCP prophylaxis can increase life expectancy. Yet, despite the introduction of AZT, AIDS patients still average approximately 22 to 24 days of hospitalization per year. A recent study from the Florida Medicaid department indicates that, despite the introduction of AZT, yearly treatment costs will continue to rise at rates similar to the general Medicaid budget. In addition, a recent study examining 240 AIDS cases in Massachusetts indicates that, due to increased survival, the overall lifetime costs of treated have risen.

A second confounder when projecting future AIDS costs is the changing composition of the AIDS population. To date, there are multiple AIDS "epidemics", including the IV drug user, heterosexual, male homosexual, and children. The percent distribution of AIDS cases by these characteristics has, and continues, to change. Unfortunately we have little information concerning the medical costs of treating PWAs who fall into different risk groups.

**6. TREATMENT OF PATIENTS WITH AIDS IS LIKELY TO ASSUME AN INCREASING SHARE OF THE MEDICAID BUDGET.**

(see Figures 6,7 and 8)

My survey of the literature indicates that treatment of PWAs will account for \$1.6 billion in Medicaid spending in 1990. This represents 4.2 percent of all Medicaid spending on the non-elderly and 2.7 percent of the total Medicaid budget. In light of the projected 46 percent rise in the number of new AIDS cases between



1990 and 1993, and rising survival times, the number of PWAs alive during the year will rise 69 percent between 1990 and 1993. In addition, continued expansions of Medicaid eligibility to higher income brackets, and increased survival time (thus increasing the number eligible under the medically needy program) is also likely to increase Medicaid expenditures. Thus, even assuming that AIDS and other Medicaid spending rise at similar rates, AIDS will assume a growing portion of the Medicaid budget. Medicaid costs of treating PWAs will double between 1990 and 1993, rising to \$3.7 billion. As a result, costs of treating AIDS patients would rise from 2.7 to 4.5 percent of total Medicaid spending.

## 7. FUTURE STRATEGIES

The HIV epidemic highlights the need for two clear improvements in policy to pay for health care. First, Medicaid reimbursement policy should encourage the provision of comprehensive care in a cost-sensitive manner as well as adequately reimburse those facilities providing a disproportionate share of care to AIDS patients. Second, AIDS highlights the need to provide for those who have neither health insurance nor entitlement to health care benefits.

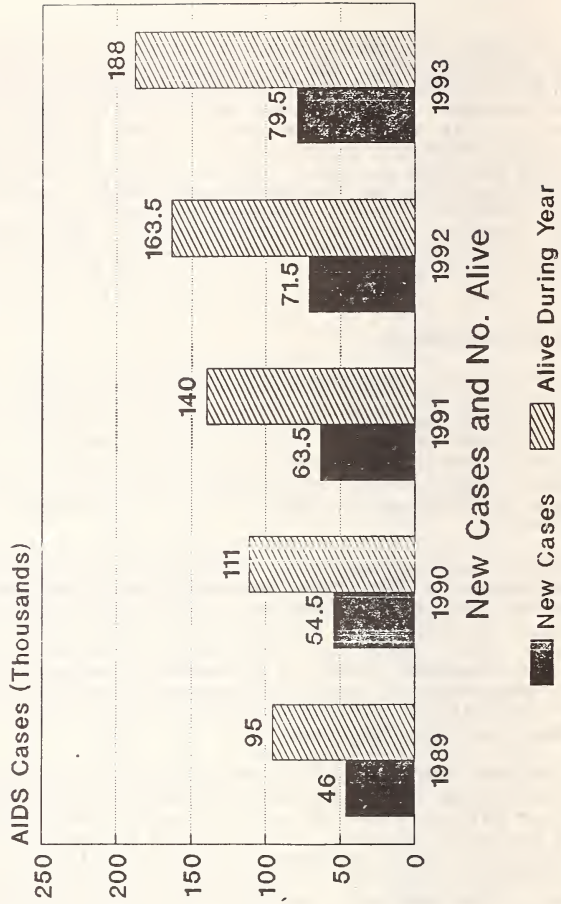
To counter the problems that arise from fragmented care and lack of comprehensive outpatient services, Medicaid should adequately reimburse for the continuum of care (ambulatory, drug treatment, hospital, chronic and hospice) that AIDS and other patients require. This would also include an investment by Medicaid in early intervention drugs (e.g. aerosol pentamidine) and primary care. These changes not only make good clinical sense, but over time, are likely to prove cost-effective as the reliance on institutional care declines.

Due, in part, to the acuity of this disease, AIDS heightens the need to provide for those who are uninsured or underinsured. The number of AIDS patients privately insured stands to fall depending on the growth in insurers using the HIV antibody test to determine insurability. While a number of options exist to extend coverage to those with AIDS (as well as the 32.7 million uninsured in general), the Medicaid program will assume an increasing role. Facilitating the application for and implementation of the Medicaid AIDS waiver option is a useful start. Expansions of Medicaid to those with incomes at the federal poverty level may also be desirable, although a costly, method of extending coverage.

This ends my formal remarks. I would be happy to address any issues the committee finds of use. Thank you again for the opportunity to address this critical health policy issue.

FIGURE 1

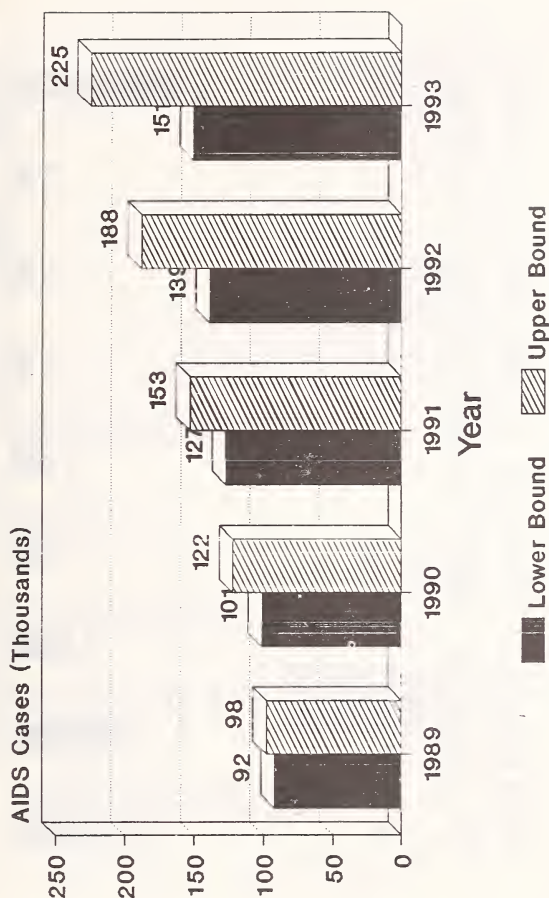
# PROJECTED AIDS CASES AND NUMBER LIVING WITH AIDS, 1989-1993



Source: Centers for Disease Control, 1990

FIGURE 2

# NUMBER OF PERSONS WITH AIDS ALIVE DURING THE YEAR, 1989-1993



SOURCE: Centers for Disease Control, 1990

FIGURE 3

# DISTRIBUTION OF NEW AIDS CASES BY STATE AND % MEDICAID ELIGIBLE

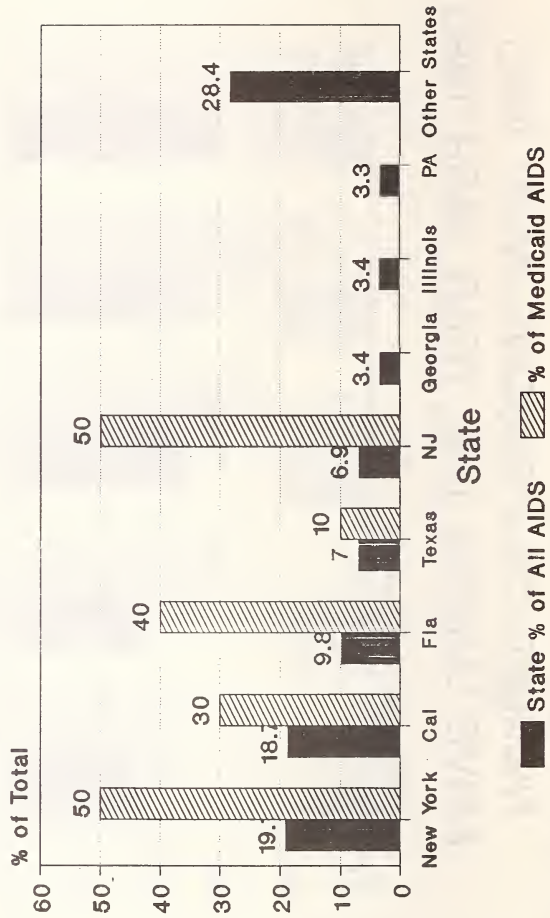




FIGURE 4

# DISTRIBUTION OF PAYERS FOR MEDICAL AND AIDS CARE 1989

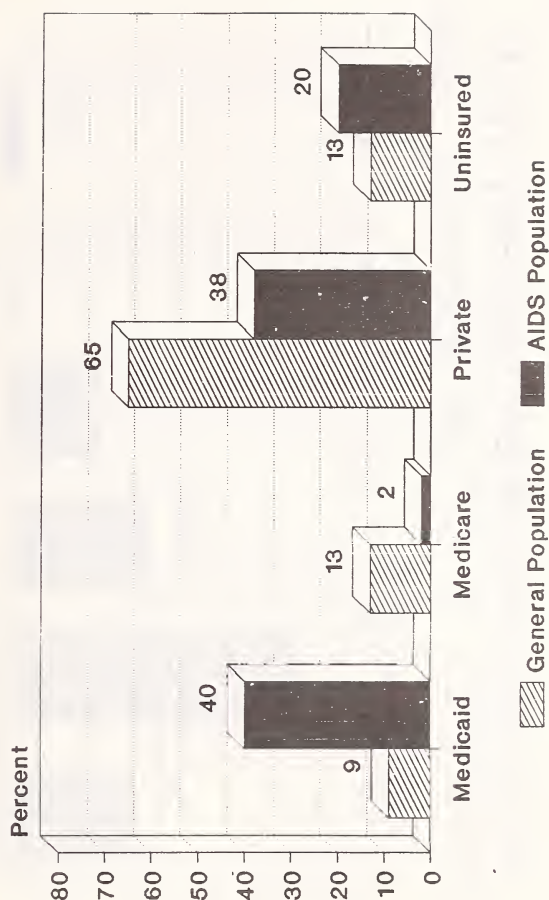
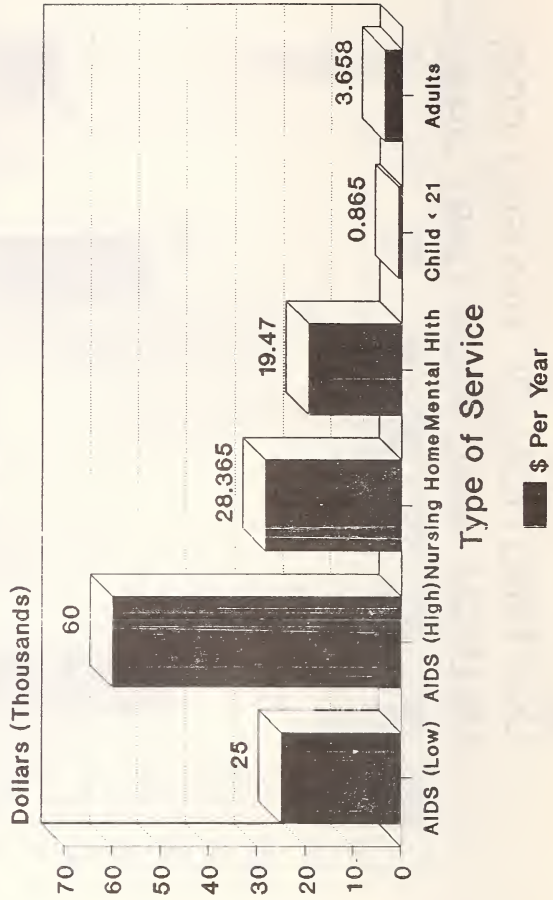


FIGURE 5

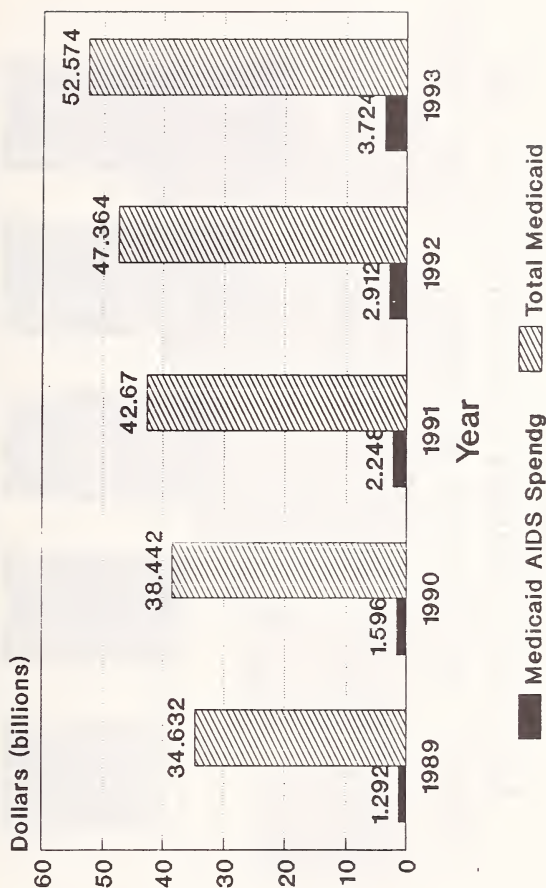
# MEDICAID AIDS SPENDING PER YEAR COMPARED TO OTHER SERVICES, 1989



SOURCE: HCFA Form 2082 (Non-Aids)

FIGURE 6

# TOTAL MEDICAID (UNDER 65) AND AIDS SPENDING, 1989-1993



Total for under 65 recipients

FIGURE 7

# AIDS SPENDING AS PERCENT OF TOTAL MEDICAID BUDGET, 1989-1993

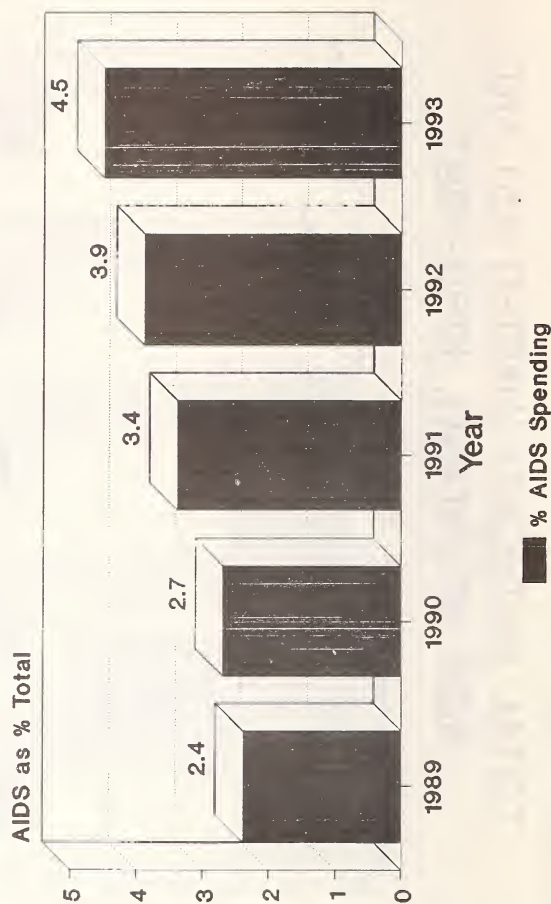
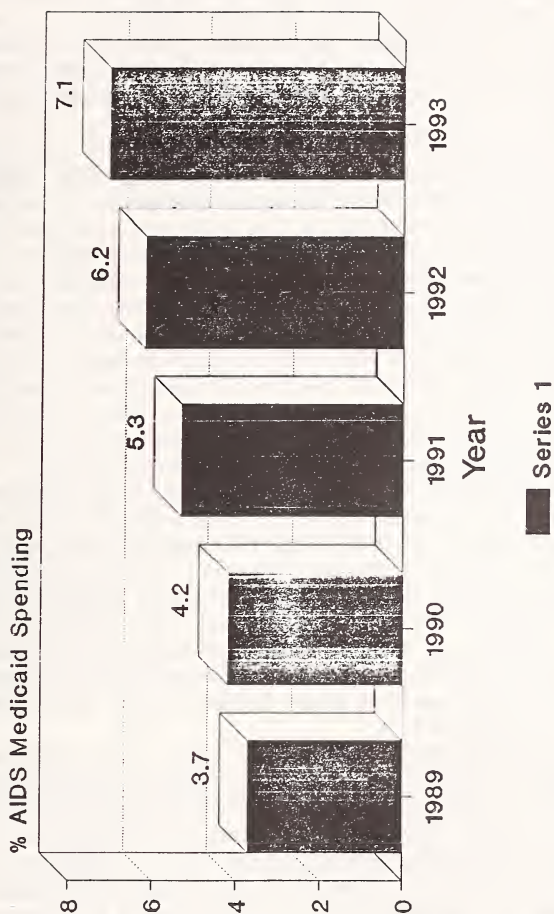




FIGURE 8

# MEDICAID AIDS SPENDING AS PERCENT OF TOTAL (UNDER) 65, 1989-1993



Mr. WAXMAN. As I understand your testimony, you're saying that under the current policy the HIV epidemic means substantially new Medicaid costs, by your estimate, an additional \$9 billion in Federal and State funds over the next 3 fiscal years. Moreover, these costs will not be evenly distributed throughout the country but will be concentrated in AIDS high incidence States in particular.

As you know, I believe there ought to be a Federal program for the Medicaid or to replace Medicaid. But until we get a broader reform, what can the Federal Government do to help the high incidence States respond to the epidemic and perhaps reduce the rates of increase in AIDS-related Medicaid costs?

Mr. THORPE. There's probably a couple of things that could be done. First of all, any type of enticement that one could give the Medicaid program to rely less on the acute care nature of hospitalization. That not only affects HIV-infected and AIDS cases, but it also affects general treatment patterns of the Medicaid program—very institutional oriented, acute care oriented—and much less care is being provided in the outpatient side. So that would be one thing to encourage outpatient treatments.

That would also include, I think, some additional investments in new drug treatments. And Medicaid, I think, would make a wise investment in doing that. You mentioned the dilemma that Medicaid has in terms of the definition of "disability."

The second thing is that there is a program—Home and Community Based Waivers—the States may apply for, but few have done so. There's a number of problems of why States haven't done that—it has to do with the administrative burdens; it has to do with problems that some States might find in documenting the effects of the waiver.

A third thing that I think that your bill, the proposal, encompasses is that there's a tremendous problem in the private health insurance system. And one of the things that could really be helpful to State Medicaid programs is to try to find mechanisms to allow individuals that have HIV or AIDS to retain their private health insurance. And your proposal is to finance a part of COBRA expansions would be very, very helpful to a number of States.

Mr. WAXMAN. One of the concerns expressed about the Medicaid AIDS legislation we introduced is that it would set a bad precedent by limiting benefits to individuals with a particular diagnosis. As you know, Medicaid law currently allows States to limit the provisions of home and community-based services to individuals with AIDS. And eight States, including California, New Jersey, and Florida already do so.

Current Medicaid law also allows States to target case management.

Given the cost consequences of the epidemic for Medicaid, can you see any reason why we should not try to develop Medicaid policies that are specific to HIV-infected people? And how else could the program which was enacted almost 15 years before the epidemic started, meet the challenges it poses?

Mr. THORPE. I think Dr. Koop made a good point this morning in terms of the concern about setting a precedent with the Medicaid program about having it being a disease-specific set of benefits.

However, I think that in terms of some of the proposals that you made, they made good clinical sense and they probably make good cost sense.

The reason that I would think of—I would support doing it—it's one of the problems that I would have is that Medicaid as a payer has a number of shortcomings, unlike the private health insurance market. First, as we've heard, there's low payment rates. Second, there's wide variations in eligibility across the States. And third, the scope of benefits that State Medicaid programs provide are, given their discretion to either limit or add to optional services is all over the map.

So I think there is so much variability in existing State Medicaid programs—some being very, very good; some being very, very poor as a payer—would be one reason to have some concern about some of these expansions. So one of the things to perhaps look at would be to take a broader examination of the Medicaid program in terms of perhaps looking at a standardized set of benefits, level of payment, and so on.

Mr. WAXMAN. My last question anticipates the next panel. In your testimony at figure 4 you have a bar chart that shows that private insurers cover 65 percent of the general population, but only 30 percent of the AIDS population. Conversely, Medicaid covers about 9 percent of the general population, but 40 percent of the AIDS population.

What's going on here? Is the private insurance industry shifting the risk onto Medicaid?

Mr. THORPE. I think there's three answers to that question.

First of all, one of the reasons why Medicaid covers so many HIV-infected, or AIDS patients, has to do with the risk groups, is the first reason.

The second reason, though, has to do with the structure of the private health insurance market. There are a number of problems in the private health insurance market, and one has to do with the increased amount of experience rating, the dissolution of community rated policies; and as a result, a byproduct of that testing for HIV and the possible denying of health insurance, and life insurance in many instances, based on the results of those tests. So that's one set of problems.

Another set of problems has to do with the structure of COBRA, why we do have a mechanism to provide expansions of private health insurance for some individuals once they're laid off or unemployed. For many individuals who have AIDS, even though that mechanism exists, it's not affordable.

In the second year of COBRA expansion, that is, I guess months 19 on, individuals can buy into private health insurance policies at 150 percent of the group rate. That's a very high price even though the group rate is generally low; and for individuals with AIDS, it's generally unaffordable.

So I think that that is a substantial problem of affordability for people with AIDS in general in the private health insurance market.

Mr. WAXMAN. Thank you very much.

Mr. Dannemeyer.

Mr. DANNEMEYER. Thank you.



Now, if the Federal Government would provide additional financial assistance to deal with AIDS patients under Medicaid, then States have to pick up a piece of that, obviously, don't they?

Are you aware, sir, that I think within the last year 49 governors of the States of this Union, including the governor of your State, Massachusetts—Mr. Dukakis—signed a letter saying to the Congress of the United States: for goodness sakes, cut it out, don't lay any more health care costs under Medicaid on the States of the Union.

Are you familiar with that?

Mr. THORPE. As you mentioned, almost all the governors—Governor Celeste from Ohio, perhaps leading the charge as well.

Mr. DANNEMEYER. How do we reconcile the fact that the governor of your State, governors of 49 States are saying to the Congress of the United States, don't lay any more burdens on us with Medicaid: And yet this legislation would lay an additional burden.

How do we reconcile that?

Mr. THORPE. Again, I think that the discussion should be expanded a little bit beyond AIDS, because it's a more general discretion about how to finance care for individuals without health insurance and how to finance care for people that can't pay for it.

Mr. DANNEMEYER. If we establish a separate policy under Medicaid for AIDS, aren't we going to be witnessing advocates for special diseases later this year, or next year, talking about similar provisions for those with diabetes, or those with heart trouble, or those with cancer?

Isn't it almost predictable that disease-specific advocates will be coming for us to do that as well?

Mr. THORPE. I'm sure that that's true, and that's happened over the years anyway. I guess, again, since I am an advocate of having some sort of a national and comprehensive health insurance program, I wouldn't view that as necessarily being a bad thing.

Mr. DANNEMEYER. I see the one governor who didn't sign that letter—Governor Cuomo of New York—his State is now coming close to joining—well, there's talk now in the bond market that the bonds of New York State will also be lowered. Massachusetts, I think, has acquired the distinction of being lower than the State of Louisiana in the bond market, which is quite a feat. In terms of the States of the Union, New York may be in the same boat.

Where do we stop with this expenditure of public funds?

Mr. THORPE. I think it's probably unfair to place the fiscal problems of States in the northeast in the Medicaid program. The fiscal problems of States in the northeast in terms of why the projected budget deficits are so high have much more to do with revenues.

Mr. DANNEMEYER. I'm not talking about the northeast now. Take Democrat Governor Neil Goldschmidt of Oregon, has said: Medicaid has turned out to be the monster that eat the States.

Now, shouldn't we in Congress be aware of that?

Mr. THORPE. I think in the chairman's opening remarks in introducing me, there's a broader set of debates that are going on and I think should be expanded on who should finance Medicaid.

Mr. DANNEMEYER. See, in 1975, State Medicaid costs accounted for 7 percent of total State spending. By 1989, it gobbled up 13 per-



cent; and the estimate is it will hit 17 percent in 1994. Seventeen percent of total State spending.

In 1991, they are expected to hit \$37.2 billion, which is more than triple what they were in 1980. How high is up?

Mr. WAXMAN. Would the gentleman yield just for a point on the provision that's before us?

Mr. DANNEMEYER. Yes.

Mr. WAXMAN. The Medicaid provisions that we have in this bill are all optional with the States, so the States are not mandated that they must cover HIV positive, for people with early intervention drugs, or community care provisions, or the COBRA extension—that's all optional. If the State wants to cover it, they may; if they don't want to, they don't have to. If they choose to, they'll get matching funds under the Medicaid program.

There is one part that is mandated, and that's the increase in reimbursement to hospitals that have a large number of AIDS cases. And there, I suppose, the governors may complain.

But I did want to point out that insofar as the governors are concerned in terms of what—

Mr. DANNEMEYER. I appreciate that. I realize Mr. Thorpe is not involved with this problem of how the House of Representatives function. But, you know, in a democratic process one would think that members on the floor of the House would vote up or down as to whether or not we want to implement this law.

I have to, with great respect, pay homage to the perspicacity of my distinguished chairman, Mr. Waxman, because last year, for instance, we didn't bother to bring these provisions up on the floor of the House for a vote when it was considered in the reconciliation package under a closed rule.

What I'm saying is that the members of Congress weren't even given the option of voting on whether or not we wanted to do this from a policy alternative. It was put into a reconciliation package which was in business for the purpose of ostensibly finding reductions in spending, which, in this instance, added a great deal of increased spending and in Conference Committee was struck out.

I mention this only for your observation, sir, that it's an interesting process to watch the legislature in session.

Mr. WAXMAN. Mr. Scheuer.

Mr. SCHEUER. Thank you, Mr. Chairman.

The questions that my colleague, Mr. Dannemeyer, raises are profoundly important questions of biomedical ethics. I don't come out the same way as he comes out but I do agree with him that Congress hasn't faced up to these issues.

It seems to me that we are in a desperate search to place health care expenditures in some kind of a reasonable relationship with other very important societal needs, like education, like infrastructure. And within the rubric, within the confines of the health care system, we're desperate for some kind of way to place life termination care with life commencement care—prenatal services, postnatal services, family planning services.

And it seems bizarre that we would take a life that is in its final stages of evolution—let's say a child with AIDS—that's going to cost us approximately \$80,000—some reasonable percentage of that. I'm told a disproportionately large share of that is in the latter

final stages as that life is dwindling to the vanishing point—maybe it's \$10,000, \$20,000, or \$30,000.

While at the same time, while we're lavishing those expenditures on life-dwindling measures, we're denying essential life-enhancing measures for a 3-year-old or a 4-year-old or a 5-year-old child who is in desperate need, let us say, an enriched preschool education program like Head Start to enable them to have a chance of making it at school, and living independent, productive lives full pride and satisfaction, instead of being almost mathematically consigned to education failure. When they come from disadvantaged homes, they are severely at education risk.

And the experience that we are looking at across the length and breadth of this land indicates that if we don't intervene with those kids, at their very earliest formative stages of their lives, certainly by the third, fourth, and fifth year—and many people have said even before that—we're virtually consigning them to failure, with all of the societal costs that ensue—delinquency, crime, welfare, public housing, and the like.

Has your medical school or school of public health done any thoughtful examination of this agonizing public policy issue of one, how do we try, by means you perhaps heard from the last panel, to provide low cost, high quality care; to lessen the impact of AIDS on our health care system, on our tertiary hospital bed supply, on our emergency rooms—that these cases are distorting beyond belief—on the utilization of trained professionals—doctors and nurses?

Have you thought about how we can provide high quality, albeit lower cost care, for AIDS patients to diminish the sucking up of resources that are urgently needed elsewhere in the health care system for life-enhancing treatment as opposed to life diminishment treatment, as well as the demands outside of the health care system?

Mr. THORPE. I've certainly thought about it and I've thought a lot about it, and I think if I had the answers I could sell a lot of books and perhaps speed up my tenure decision.

They are complicated issues. The issues that we talked about today with respect to AIDS exposes a whole set of shortcomings with our health care delivery system. So they are not problems specific to AIDS; they're problems that turn into a wider range of treatment patterns in the economy.

I think that there are a number of reforms that, again, that are specific to AIDS that would have to develop in order to remove our attention and focus on the acute care delivery system, promote a continuum of care, promote outpatient delivery service that's not only for AIDS patients but for other patients as well, and they have to do with the structure of health insurance benefits; they have to do with the structure of the Medicaid program—which is heavily acute care oriented and less community-based oriented. It has to do with styles of practice of physicians.

Practically, how do you make that move from an institutionally focused style of practice to a community-based, an outpatient style of practice, is a difficult thing to implement.

New York State is currently undertaking a substantial effort—spearheaded by Commissioner Axelrod—to do that. He's trying to reduce the importance, if you will, of acute care facility in terms of



treating patients across the board and trying to, at the same time, promote outpatient and community-based services. He's doing it by changes in the way that we reimburse for outpatient care vis-a-vis the inpatient care. He's doing it through providing incentives for hospitals and teaching centers to train more primary care physicians and less specialty care physicians, and so on.

So there are some policy offers which exist and there are some States that are trying to address the broad range of issues that you've raised and that New York is the best example that I have of one.

Mr. SCHEUER. I appreciate your answer. And I've got to say that the Congress has not faced up to those issues. I think we have the intelligence; I'm not sure we have the courage, because these are agonizingly sensitive and delicate issues. But sooner or later, society has to face up with them and in the meantime we are all very, very frustrated.

Mr. WAXMAN. Thank you, Mr. Scheuer.

Mr. Nielson.

Mr. NIELSON. Thank you, Mr. Chairman.

I think we have the intelligence and we have the courage; we don't have the money—that's why we're passing it on to the States. We have, in addition to H.R. 4080, as Mr. Dannemeyer has mentioned, we have five new Medicaid bills—H.R. 3931 to H.R. 3935, respectively—each of which has a new Medicaid mandate.

I heard the governors say just this week to the President, give us part of that peace bonus, if there is one, and give part of it to health care, and things of that nature. We need to do some of the things that Congress mandates but doesn't provide the wherewithal for.

How will the States face all these new mandates? There's 185 percent of Federal property line for pregnant women and infants, 100 percent property line for children born after September 30, 1983; Hospice care; disproportionate payment adjustment for AIDS hospitals, and conditions for participation for ICIMR facilities for the retarded.

How can we possibly pass these on to the States in view of their financial condition and in view of the plea they are making to the President right now in the Governors' Conference?

Mr. THORPE. You are raising a series of questions that's very difficult to answer but let me give it a shot.

Mr. NIELSON. Okay. Let me ask first the basic question. Is it fair for the Federal Government to make all the rules and make the States pay all the penalties?

Mr. THORPE. Again, the Medicaid program, being a joint Federal/State program, are both playing a substantial—

Mr. NIELSON. But the increases are in the State level, not the Federal.

Mr. THORPE. I guess the point is that there are a lot of people in this country without health insurance. There are a lot of people in this country, as you can tell by our projections, that are going to need medical care as they contract AIDS. The costs are going to be very high. The costs of people that aren't getting care are very high downstream in terms of not providing preventive care for them right now.

There's no question about that; that anything that we do to try to include those that are uninsured and include those that need medical treatment, and those that need medical treatment quickly is going to cost money, and it's going to cost a substantial amount of money. I don't think that there's any debate about that.

You're raising issues about what's the fairest way to finance it, and it's an appropriate question to raise and it's a tough question to grapple with. It's something that the Pepper Commission is currently grappling with and it's something that individuals have grappled with over the years about how to include those into a broader base system that need medical care that should be included. Unfortunately, there's not that many suspects to pick on. It's States, Federal governments, localities, individuals, employees, and employers are the usual ones that we've looked to, and I think that each of those can make credible arguments about why they shouldn't have to assume a disproportionate burden of financing care for either the uninsured or for very high expensive cases in the private health insurance market.

So I think everybody can make that case. The Federal Government has budgetary problems; State governments have budgetary problems; localities are facing problems; employers would face additional burdens of financing this through higher costs and perhaps lower profits; employees would face additional burdens of this through perhaps lower wages over time, and so on. Everybody, no matter where you impose the cost of this, is going to have some sort of economic repercussions; and I think that the issue is what's the fairest way and the most equitable way of financing this.

Mr. NIELSON. So I guess going back to Mr. Scheuer's point, that we don't have the courage—we are very brave about passing them on to the States is what we're doing right now.

Let me ask a question that was asked Dr. Koop. I asked Dr. Koop and then later Mr. Dannemeyer asked Dr. Conviser, and that is, is it fair to treat AIDS victims differently than you do heart, diabetes, cancer victims, and so on? In other words, make them achieve Medicaid even though not disabled where you don't allow that same provision for the other things. Is it sufficiently different that we should treat it differently and change the public policy on it?

Mr. THORPE. If you are focusing on an incremental question—and I'm somewhat agnostic on that—in terms of the broad issue of including all of those individuals who need treatment in some sort of health insurance system——

Mr. NIELSON. That's not my question.

My question is, should we now have a new way to treat by saying you meet the financial requirements for Medicaid, even though you don't meet the disabled requirements, should we treat AIDS differently and preferentially above other things? For example, diabetes, if treated early—and if an adult get diabetes and if he recognizes it early and gets involved with it, he doesn't have to use the needle all the time—there are oral methods he can use. But if you wait until he becomes disabled, then you have a very expensive and a very painful process of treating.

The same thing could be said about cancer victims and heart victims too.

I just wonder, are we being too preferential in the AIDS case?



Mr. THORPE. I don't think it would be preferential in a sense that most of the people that contract HIV and who ultimately—it's just a number of years before they actually come down with AIDS—

Mr. NIELSON. So it's the surety that they become disabled later that causes the difference?

Mr. THORPE. With a few exceptions, and I'm not—since we haven't had the waiting period long enough yet—with few exceptions, everybody who contracts HIV will at some point in time likely contract—

Mr. NIELSON. So if I have a heart attack, the fact that I may not have another one for 10 years, means "I don't have the right to be taken care of presently, . . ." is that what you're saying?

Mr. THORPE. Until you get poor.

Mr. NIELSON. I'd like more time on this but I don't have it right now. Thank you, Mr. Chairman.

Mr. WAXMAN. Thank you, Mr. Nielson.

Dr. Rowland.

Mr. ROWLAND. Thank you.

I have just one question.

How would you anticipate the projections that you made here about Medicaid and the increasing cost of Medicaid to change if AZT were made available to people who were HIV positive who had not developed the disease?

Mr. THORPE. That's a difficult question because it creates numbers that will go in different directions.

Let me first say, however, that on my first chart that the number of people alive during the year—those projections that the mathematical models have developed—that try to incorporate some of those changes and treatment patterns into their estimates, one of them being the earlier use of AZT, the increasing use of other types of treatments, very symptomatic patients, and so on.

So those have been incorporated to the extent that we have the mathematical and epidemiologic data to do so into the estimates of the number of people alive during the year.

Mr. ROWLAND. Could I interrupt you at that point and say that one of the things that this piece of legislation intends to do is to make AZT available to those people who are seropositive but haven't developed the disease, and that's not incorporated into your figures there, is it?

Mr. THORPE. It is in a sense that since it's the onset of AIDS, it's in there in the sense that the number of people downstream that contract the disease and are alive during the year are included.

Mr. ROWLAND. So you are assuming that this legislation will pass and that that will be made available to people who are HIV positive?

Mr. THORPE. The people who made the projections had to make some assumptions about the diffusion of treatment patterns regardless of what Congress does. I mean, these treatment patterns are in place today in public hospitals and other types of facilities that don't rely solely on the public part of financing directly through the insurance market.

So there were some assumptions that were built into the estimates.

The AZT question is difficult because it cuts two ways: On the one hand, the more broadly based use of drug therapies is very effective in promoting outpatient use of services. So in that sense it's less expensive. You are moving patients out of the hospital faster than would have been the case without AZT. So in that sense it's less expensive. It's more expensive in the case that we know that over time the 1-year survival rates of people with pneumocystis pneumonia has increased quite dramatically.

Those individuals in 1984 that had PCP had 1-year survival rates of about 43 percent. And as of today, that's something that has changed to almost 70 percent. So the survival rates are increasing over time, and that's one of the beneficial aspects of the changes in treatment patterns, is people with AIDS are living longer.

Mr. ROWLAND. I guess that works with most everything else, too, if people live longer they are subject to have more diseases and it will cost more in the long run.

Thank you, Mr. Chairman.

Mr. WAXMAN. If the gentleman will yield, there was an interesting article in The Post this morning saying that the antismoking efforts may end up costing us more money because some of these people are going to live a little longer—that was pretty gruesome.

Mr. ROWLAND. Yes, I saw that.

Mr. WAXMAN. Mr. Towns.

Mr. TOWNS. Thank you very much, Mr. Chairman.

As we talk here, the word "choice" keeps coming up in terms of whether we treat this illness or stop treating that disease. And I must admit that bothers me a great deal. The fact that we're even talking that way, simply because of cost. And I'd like to say, in the northeast in particular, you are right, that our financial situations should not be attributed solely to Medicaid and Medicaid costs—it's more than that, and that's a debate for another time.

But if we expand Medicaid coverage to those women and children with incomes at the poverty level, because of the cost factors involved, do you foresee us pitting the two groups against each other—women and children versus AIDS patients—due to the competition in funding?

Do you anticipate that happening?

Mr. THORPE. Again, depending on what your proposals of expansion is, number of proposals to expand to poverty, including this one. I think again the issue is going to be how to provide health insurance coverage for low income individuals who don't get the needed care and require some level of services, either in the hospital or in physicians' offices. That's a debate that we've been having for years, looking at what we have in terms of the structure of the Medicare program versus of what we have in terms of the structure of the Medicaid program—that's a debate that's gone on for at least 30 years, about the equity of financing for the low-income health care program versus the equity in financing for the Medicare program, and that is an ongoing debate. I'm not exactly sure how this proposal would serve to escalate that debate and fragment it anymore than it ever has been.

I think that to the extent that we are having this debate again continues to expose the fact that we have a fragmented health care system that certain elements of society and certain very ill people



are cut out, don't get needed services, don't have access to medical care—and I think that those debates simply serve to expose some basic problems with our health care delivery system.

Mr. TOWNS. However, if we are committed to improving health care as a policy matter, shouldn't we expand treatment to both groups if we are really serious about improving health care in this Nation?

Mr. THORPE. Again, since other than through my general income tax and other types of support, I don't bear the financial burden of this directly, I would say, yes.

I find it difficult to segment the debate over health insurance and health coverage for individuals, whether they be low-income individuals that have contracted HIV, or so on, based on disease. I think that the debate is most usually addressed and attended to in a broader dialogue about the uninsured, adequate health care, and the sticky question about who should finance it, and what's an equitable financing mechanism.

So I would rather not focus in on individual subpopulations, although, clearly, those are the ones that—you could make a good argument that the ones that are most in need in terms of low income, most eminent need of the health care delivery system, should be the ones that we focus on first; but I would hope that there is a broader discussion of the health care delivery system and health insurance for individuals without health insurance in general.

Mr. TOWNS. Thank you very much.

My colleague from New York left. He was talking about choices. I think that we should not forget that there's ongoing research, hoping that eventually one day that we will be able to conquer this disease. I just pass that along for him—I'm sorry he left. But I'm really concerned about the fact that people want to cut off support for some and sort of just leave others out there without any kind of service of any sorts—that really disturbs me deeply.

Thank you very much.

Mr. WAXMAN. Thank you, Mr. Towns.

Mr. Dannemeyer.

Mr. DANNEMEYER. Last year, I think you wrote an article for the American Medical Association Journal advocating a substantial increase in Medicaid funding—the total cost of which was estimated at about \$29 billion a year, half of which would have been paid by the States; is that right?

Mr. THORPE. I did write such an article.

Did I advocate this?

No, I was reporting on a series of proposals that the Health Policy Agenda had come out with—the analysis I did——

Mr. DANNEMEYER. Would you say that a reader of the article would say you're in favor of those proposals?

Mr. THORPE. I've written on a lot of things and done a lot of——

Mr. DANNEMEYER. I'm talking about that one, one specific one.

Would a reader believe you favored the proposals?

Mr. THORPE. No, I think if somebody read that article very carefully, I think what they would come away with is that Medicaid expansion for all below the poverty line would one, be very expensive, and two, would probably not be an equitable sharing of the

burden for providing health insurance for low-income people. The point of the article was to show the fiscal implications of the Medicaid expansion.

Mr. DANNEMEYER. You are opposed to that expansion?

Mr. THORPE. No, it wouldn't be fair to say I'm opposed to the expansion. The point I was going to make is that I thought the fairest way to have the expansion would be to couple it with a broader based financing strategy which would include the private sector as well.

Mr. DANNEMEYER. If you're not opposed to it, it seems to me you would be supporting it.

Thank you.

Mr. WAXMAN. Dr. Thorpe, thank you very much for your presentation to us. You have been very helpful in giving us a picture of what the costs are going to be for Medicaid. Thank you for being with us.

Mr. THORPE. Thank you.

Mr. WAXMAN. In 1986, Congress enacted the so-called COBRA Continuation provision. Under this requirement, employers with more than 20 employees must allow employees who have lost their jobs to continue to purchase whatever health insurance coverage the employer offers to its employees for 18 months. The former employee must pay 102 percent of the group rate for the insurance.

Last November, as part of the 1989 Budget Reconciliation Act, we extended the coverage period to 29 months for individuals who were disabled at the time they lost their jobs.

During the 19th to the 29th month, the former employee's cost is 150 percent of the group rate. This extension, which was authored by Congresswoman Nancy Pelosi, was intended to help people to purchase private health insurance coverage during the entire waiting period for Medicare coverage.

In the legislation I've introduced last week, there is a provision allowing States to use Federal Medicaid matching dollars to purchase COBRA continuation coverage on behalf of low-income HIV-infected individuals.

Our last panel this morning is composed of officials from Michigan and Washington State for managing State-run buyin programs for persons with HIV infection or AIDS.

Scott Merwin is a project manager of the Michigan Insurance Assistance Program for persons with AIDS. He is accompanied by Denise Johnson, project coordinator. David Baird is the administrator of the Washington State HIV/AIDS Insurance Continuation Program.

I want to thank you all for being here this morning. Your prepared statements will be made part of the record in full but what I'd like to ask each of you to do is to limit your oral presentation to no more than 5 minutes.

Why don't we start with Mr. Merwin.



**STATEMENTS OF SCOTT D. MERWIN, PROJECT MANAGER, INSURANCE ASSISTANCE PROGRAM FOR PERSONS WITH AIDS, MICHIGAN DEPARTMENT OF SOCIAL SERVICES, ACCOMPANIED BY DENISE JOHNSON, PROJECT COORDINATOR; AND DAVID J. BAIRD, PROGRAM ADMINISTRATOR, HIV/AIDS INSURANCE CONTINUATION PROGRAM, WASHINGTON STATE DEPARTMENT OF HEALTH**

Mr. MERWIN. Thank you, Mr. Waxman. I just want to say how deeply we appreciate the opportunity to come before this subcommittee to give testimony about our projects.

I think it's perhaps safe to say that the greatest weakness we have in our American health care financing system right now is the 30-odd million Americans that don't have any health insurance at all.

And one of the more perverse dynamics that's going on that has to do with the uninsured is that the very people who need their health insurance the most, which are the people who are very sick and the people who are actually dying, are those who are at the greatest risk of losing their medical insurance.

Now, COBRA and OBRA are Federal laws that are intended to help out with that, and they do a great deal. But the difficulty that you have is that these laws allow you to reach into your pocket and continue your health insurance at your own expense. But if you're too sick to keep working, it's not going to take too long before you don't have the money to be able to pay your own health insurance.

So what our program is about is to target the people who have AIDS and who at risk for losing their health insurance because they are too sick to keep working. If somebody's in that situation and they meet our eligibility guidelines, we will step in and pay their insurance premium for them.

We are extremely pleased to see that there's legislation being considered on the Federal level to make Federal funding available for programs like this because so far we've been doing it exclusively with State dollars.

I do want to strongly urge consideration of a couple of revisions in the legislation the way it's been drafted so far. For one thing, the legislation in its current form restricts Federal match only to people that are in COBRA or over extension periods.

Now, COBRA and OBRA only apply to companies with more than 20 employees and they don't apply to privately purchased insurance at all. We have 30 people in our program; 8 of them are either buying insurance privately or they were in a small company, so they wouldn't have been affected by this.

Any insurance product a person has who has AIDS it makes sense to keep that in place. So we believe that the law should not just be restricted to the COBRA maintenance situations.

The other changes, I believe that the means test is probably too low in the Federal legislation the way it's set up right now. We use 200 percent of the Federal poverty guideline for eligibility criteria and a \$10,000 cash asset test. Only about half of our eligibles are actually at 100 percent of poverty or below. But what we have is each person who is in the program, because of their sickness they are right on the verge of incurring very high medical costs. And

once they incur those costs they will certainly become Medicaid eligible if they aren't eligible already. So you want to get the people in the program who are at risk for having high Medicaid costs.

The second point having to do with the means test is that in areas like New York City, for example, you have high housing costs, and these can cause people to be impoverished even though their income is relatively high.

It has been our experience talking to people in our program that if they had to make a choice between a decent place to live and paying their insurance premium, they will choose a decent place to live. So these people are going to also be at risk for losing their insurance even though their income is relatively high, or maybe relatively higher.

Our program began in the Detroit area October 1 and so far we've had 30 people qualify for the program. A quick cost-benefit analysis I did for the months of November and December showed about a 19 to 1 cost-benefit ratio that we experienced during those 2 months. But not only is the program cost-effective, and very useful for that reason, it also helps people, and I would like Denise Johnson just to give some remarks about the effect it's had on the people in the program.

Ms. JOHNSON. Again, I'd like to say thank you for allowing us to be here.

Some of the reactions to the program from the client's standpoint is that—I'd like to give you one example. I have a gentleman whose income is above the Federal poverty level but not quite 200 percent—he's at about \$700 a month. His shelter cost, rent only, is \$350. His heating cost ranges about \$200 to \$250 a month in the wintertime—that includes heat and utilities. And the he has his food cost and his health insurance cost.

This gentleman indicated to me that our program helped him in the sense that he had to make a choice between whether he would stay in the place that he lived while he was working, while he was gainfully employed, or whether he would move to a less desirable section of town in order to keep his health insurance. So the choice for him was: stay in a decent place to live and drop my health insurance, basically. And our program was there for him and allowed him to not only stay in a decent place to live but also have his health insurance intact. And that is not exclusive to one individual.

I also find that the physicians, in response to the program, are quite appreciative because the reimbursement level for private health insurance, of course, is much higher than Medicaid would be.

Mr. MERWIN. Thank you.

Mr. WAXMAN. Thank you very much.

[Testimony resumes on p. 139.]

[The prepared statement of Mr. Merwin and Ms. Johnson follows:]

## TESTIMONY

Presented by Scott D. Merwin, Project Manager  
And Denise Johnson, Project Coordinator  
Insurance Assistance Program for Persons with AIDS  
Michigan Department of Social Services

INTRODUCTION

Chairman Waxman and members of the Subcommittee, we are Scott Merwin, and Denise Johnson of the Michigan Department of Social Services, State of Michigan. We are respectively the project manager and project coordinator of the Insurance Assistance Program for persons with AIDS which is operated by our Department. We are pleased to have the opportunity to provide testimony to the Subcommittee regarding this project.

BACKGROUND

Perhaps the greatest weakness in the U.S. health care system is that about 37 million citizens lack any medical insurance. . One of the most perverse dynamics in our system is that the very people who need medical insurance the most, the sick and dying, are the people at greatest risk for losing their insurance.

Federal law (COBRA 1986, and OBRA 1989) allows most people to continue their health insurance at their own expense for 18-29 months after they leave a job. But when people are too sick to work, they may soon lack the resources to pay their insurance premiums. Eventually, many of these, having lost their own private insurance, qualify for Medicaid.

In Michigan, about ten percent of the general population is Medicaid eligible, yet nearly 50 percent of the persons with full blown AIDS become Medicaid eligible. The cost of paying for AIDS related care is clearly falling disproportionately on government financed programs.

The Insurance Assistance Program for Persons with AIDS is a pilot program operated by the Michigan Department of Social Services (MDSS). The program is designed to assist people who, because of AIDS related disease, are unable to continue working, and thus may lose their health insurance.

The program will assist any qualified person to pay for any health insurance they have. The program does not purchase or provide insurance for people who do not have insurance to start with.

The program began October 1, 1989 in the three Detroit area counties of Wayne, Oakland, and Macomb, and will run for two years.

Attachment A presents basic statistics concerning the program.

#### FEDERAL FUNDING AS DESCRIBED IN H.R. 4080

We are pleased to see federal legislation being considered that would make federal match available for programs such as ours.

Insurance assistance programs for persons with high cost diseases are clearly cost effective from the perspective of Medicaid programs and the State and Federal governments which finance them. However, at this time Michigan and Washington are the only



two states with programs. A key reason is lack of federal matching dollars. States must pay 100 percent of the premiums, but only receive at most 50 percent of the Medicaid savings. States are extremely cautious about committing state dollars when no federal match is available. As a result, many, if not most, states will not adopt insurance assistance programs in the absence of federal match.

Additionally, the availability of federal match would clearly mark insurance assistance as a mainstream approach for states to use. Without match there is the sense that insurance assistance is a radical, experimental policy for a state to adopt. This creates a favorable context for those who oppose such programs.

While we are pleased with the intent of the legislation, we strongly urge several changes in the legislation as currently drafted. The eligibility guidelines proposed would exclude most of the people in the Michigan program unless state funds were used. We propose the following changes:

1. Federal match should not be limited to persons covered by COBRA and 1989 OBRA amendments.

These laws do not apply to companies with fewer than 20 employees, or to privately purchased insurance. It is cost effective to continue virtually any insurance product a person with AIDS has. Over 25 percent of the enrollees in

our program have privately purchased insurance that is not affected by COBRA/OBRA. Several other enrollees worked for small companies not covered by COBRA/OBRA that nonetheless allowed the enrollee to continue group insurance. It is equally important that these individuals qualify for the program as people protected by COBRA/OBRA. States who chose to pay premiums for these individuals, as it is clearly cost effective to do, would presumably have to do so with state dollars. This would make administration of the program needlessly complicated.

2. Financial eligibility guidelines should be left up to the states to establish.

The number and characteristics of persons with AIDS varies dramatically from state to state. In cities like New York the high cost of housing can place people in the position of being impoverished even though their income is not at a poverty level. It is our experience that many people will choose decent housing over paying insurance premiums if forced to make a choice. Our program allows income of up to 200 percent of federal poverty guidelines. We believe this effectively allows people who need assistance to qualify, while excluding persons who can afford their own premiums. Other states may find this level too high, or too low. Again, any state that chose to have a higher income limit would have to use state funds which needlessly complicates

the program. The same arguments apply to assets as apply to income. These levels should be left for states to set.

3. Medical eligibility should be based on being too ill to work in the job that provides insurance. An exception should be made for HIV infected people, regardless of disability, who believe they were discharged because of their infection.

Insurance assistance is cost effective only for people who have high medical bills and are at risk of losing insurance. The proposed legislation allows people to qualify provided they test positive for HIV, but regardless of whether they are ill, or experiencing high medical costs. Michigan restricts eligibility to persons who a physician has certified as being too ill to work in their current job, or likely to become too ill within three months.

#### LEGISLATIVE BACKGROUND ON MICHIGAN PROGRAM

The idea for the program came from State Representative David Hollister. Mr. Hollister authored Section 1626 of the DSS Appropriation Act for FY 88/89 (Act 322 of the Public Acts of 1988) which required the following:

"The department of social services shall develop a proposal to identify potential medicaid recipients who test HIV positive and pay their insurance premiums so that they can maintain their health insurance policies. The proposal shall be approved by the house and senate appropriations committees before being implemented."

A proposal was developed by the Department of Social Services, and received legislative approval on May 30, 1989.

#### ELIGIBILITY CRITERIA

For the buy-in concept to be cost effective for the State, the program must avoid buying in for too many individuals who either would have maintained coverage at their own expense, or individuals who would have had to spend-down substantial assets before qualifying for Medicaid. The purpose of the means test is to prevent the State from paying insurance premiums for people who are financially able to pay for their own. Those with good disability insurance may never qualify for Medicaid, nor need insurance assistance.

To qualify for the program, a person must have income less than 200 percent of federal poverty guidelines. For an individual this is about \$1,000 per month. The allowed income is greater if the person has dependents. Medical expenses and insurance premiums can be deducted from gross income in determining whether the income guideline is met. The person must also have less than \$10,000 in cash assets.

The person must also be at risk for losing health insurance because of AIDS related disease. This may be documented either by:



-A physician's statement that the person is, or probably soon will be, too ill to continue working in the person's current job because of AIDS related disease; or,

-An indication that the person was discharged from his/her job because the employer believed the person was at risk to develop AIDS related disease; and submission of a physician's statement that the person has HIV infection. [Such a discharge is an illegal employment practice. However, the person can qualify for the AIDS Insurance Assistance program, and MDSS will work with him/her to seek an appropriate remedy.]

The Insurance Assistance program is aimed at assisting any person who has health insurance to keep it. Many people with health insurance are not protected by COBRA, for example people working at small companies, or people who buy insurance privately. These people can also qualify for the AIDS Insurance Assistance program. Persons who buy insurance privately are generally entitled to continue it as long as the premiums are met. Persons working for companies not legally covered by COBRA often still have the ability to continue some form of health insurance.

### APPLICATION PROCESS

A person applies for the program by completing a special application and returning it to the Insurance Assistance office. An application may be requested from this office by calling (313) 256-1380. Applications are also available at local Department of Social Services offices. See Attachment B for a copy of the application package.

### PAYMENT PROCESS

In most cases, the program obtains a copy of the insurance bill, and makes payment directly to the company. The Insurance Assistance Program works with the person, their former employer, and insurance company to arrange a payment method.

### SIZE OF TARGET POPULATION

#### Projected

The target population is those persons with AIDS, with insurance, who would have become Medicaid eligible. To estimate its size we take the expected number of Medicaid eligible AIDS cases, and reduce it to account for cases that probably had no insurance. An assumption is made that no IV drug users had insurance.

In advance of program implementation it was estimated that the maximum size of the target population as being equal to 20 percent of the number of full blown AIDS cases expected 12 months later.

The target population was estimated by taking the total number of AIDS cases and removing those who would not be affected by an insurance assistance program. These are: those AIDS cases which do not become Medicaid eligible (50%), IV drug users (28%), pediatric without insurance (1%), or undetermined transmission mode without insurance (1%). The result is to remove 80 percent of total cases. Or conversely, the estimated target population equals about 20 percent of new AIDS cases.

This method would estimate about 60 cases would be eligible by the end of February. Enrollment in 1990 would average about 15 per month.

#### Actual

During the first three months of operation actual enrollment was roughly consistent with this estimate. In January and February the pace of enrollment has been lower than this method would estimate.

As of 2/21/90, thirty persons had qualified for the program. Two of these have returned to work and are no longer eligible. Enrollment thus stands at 28 people.

There are several possible explanations of why the enrollment rate is less than predicted. These include:

- The Detroit area may have a higher concentration of IV drug use transmission. These cases are much less likely to have insurance in the first place.
- Men in the Detroit area who contracted HIV via sexual transmission may, to a greater extent than predicted, have good disability insurance programs that prevent them from meeting the means test.
- People may not be in a state of financial eligibility until several months after they stop working. While these persons are not eligible now, they may become eligible in the future.
- Persons who are impoverished may find it simpler to allow insurance to lapse and become Medicaid eligible. This could be particularly true for persons whose insurance has high copays, or no drug coverage.
- Persons may be unaware of the program.



COST ANALYSIS

Due to time constraints we have used a very conservative and simple method of assigning costs based partly on self reporting, and partly on the services uniformly needed by a person with AIDS. While this method does not reflect the true experience of the program, it clearly demonstrates the substantial cost to benefit ratio that existed during November and December 1989.

Each person in the program is required to submit a monthly report form identifying medical services they obtained, and describing their financial status. During the months of November and December we received 29 monthly report forms from 19 people. This represented a return rate of 29 out of 34 forms, i.e. 85 percent. The cost analysis was performed based on these. See Attachment C for a copy of the monthly report form.

DEMONSTRATION OF COST EXPERIENCE, NOVEMBER-DECEMBER 1989

	Retrovir/ Pentam.	Or. Visits	Lab	Inpatient Hospital	Total Expenses	Premiums
Total Cost	\$8,773.72	\$865.80	\$2,900.00	\$79,487.00	\$92,026.52	\$4,906.13
Cost Per Person Per Month	\$302.54	\$29.86	\$100.00	\$2,740.93	\$3,173.33	\$169.18

TOTAL SAVINGS TO MEDICAID PER PERSON MONTH - \$3,004.15

MEDICAID COST BENEFIT RATIO - 19:1

(See Attachment D for details of methodology)

Cost savings to Medicaid are a function of the number of months that persons participate in the program, and the average savings per month.

If we assume that enrollment will continue to increase at the rate of about six persons per month through 1990 there would be 88 enrollees by the end of the year. The weighted average for monthly enrollment would be 55 people.

Projected 1990 savings equals 55 people, times 12 months, times \$3,004.15 average monthly savings. Total savings equals during 1990 would be approximately \$2 million.

#### REACTIONS TO PROGRAM

##### Insurance and Business Community

The reaction of the insurance and business community has been for the most part one of "wait and see". The whole point of the program is to prevent cost shifting AIDS expenses from businesses and insurance companies to the Medicaid program. To the degree it succeeds it increases business and insurance costs. These costs must be born by consumers and rate payers. As long as the program is relatively small, insurance and business appear willing to accept it. However, business and insurance is very concerned about the idea of expanding the program to cover all high cost diseases.

Enrollees

Enrollees have stated they probably would have dropped their insurance if this program did not exist. Most enrollees are on low fixed incomes, and would have to choose between insurance and basic needs such as food, and housing.

One enrollee stated that to afford his insurance he would have had to move out of his house into a substandard apartment. He had worked hard all his life, and refused to live in substandard housing just to be able to afford insurance. He would certainly have let his insurance lapse and gone on Medicaid rather than move.

Enrollees express the strong desire to avoid being part of the welfare system. By allowing people to keep their private insurance the program helps preserve a sense of dignity.

Medical Providers

Medical providers have expressed support because private insurance pays substantially higher rates than Medicaid. The higher reimbursement and this helps to maintain access to high quality care.

CONCLUSION

We thank Mr. Waxman and the Subcommittee members for this opportunity. We would be pleased to offer any further consultation that members may find helpful.

For further information about the program please contact:  
Scott Merwin, Project Manager (517) 335-5115, or;  
Denise Johnson, Project Coordinator (313) 256-1380.

ATTACHMENT A  
BASIC STATISTICS CONCERNING INSURANCE ASSISTANCE PROGRAM,  
And AIDS CASES IN MICHIGAN

INSURANCE ASSISTANCE PROGRAM as of FEBRUARY 21, 1990

NUMBER OF  
ENROLLEES - 30

Two enrollees have returned to work, current enrollment is 28.

TOTAL PREMIUMS  
PAID - \$17,737.74

AGES OF  
ENROLLEES

20-29	- 5
30-39	- 18
40-49	- 5
50-59	- 2

All enrollees are male.

=====

MICHIGAN AIDS STATISTICS

TOTAL CASES  
1981-Jan. 1990 - 1,466

TOTAL DEATHS  
1981-Jan. 1990 - 866

TOTAL REPORTED  
CASES in 1990 - 509



Dear Applicant:

Thank you for your interest in the AIDS Insurance Assistance program. The purpose of this program is to assist low income people with AIDS related disease to pay health insurance premiums.

This is a pilot program that will run for two years beginning October 1, 1989. We will be evaluating the program to determine if it should be continued after the two years. To make this determination we must collect information each month from persons who are enrolled.

This package includes three forms, two of these must be completed and submitted when applying for the program. The third form will be used to collect information each month for the program evaluation. The two forms that must be completed when making application are:

1. Application form, including release of information;
2. Physician Assessment of Employability form,

The third form is called the Monthly Report form. It is included in the package so that you are aware of it. It does not need to be submitted when you apply for the program. It will be sent to you each month that you are in the program.

Completed forms should be sent to:

AIDS Insurance Assistance Program  
1200 Sixth Street  
Michigan Plaza Building, N. Tower  
11th Floor, Executive Suite  
Detroit, Michigan 48226

Please contact the AIDS Insurance Assistance program at (313) 256-1380, if you have questions about the program or need assistance in completing the application forms.

AIDS INSURANCE ASSISTANCE PROGRAM  
APPLICATION

Date _____	Date of birth _____	For Office Use Only
Name _____		
Address _____		
City _____		
Zip _____	Telephone # _____	
Social Security Number _____		

A. Total Cash Assets (Cash Value of Savings Accounts, Checking Accounts, IRA's, CD's, Money Markets, Stocks and Bonds) NOTE: You may be asked to provide documentation of the value of the assets.

\_\_\_\_\_

B. Current Monthly Income (Attach verification of income e.g. pay stub)

\_\_\_\_\_

C. Current Total Monthly Medical Expenses: \_\_\_\_\_

D. Employer's Name: \_\_\_\_\_

Address: \_\_\_\_\_

Telephone: \_\_\_\_\_

E. Name Of Health Insurance Company

\_\_\_\_\_

F. Name of Applicant's Physician: \_\_\_\_\_

Address: \_\_\_\_\_

Telephone Number: \_\_\_\_\_

I certify that to the best of my knowledge, all answers on this form are true and complete.

Applicant's Signature: \_\_\_\_\_

AUTHORITY: PUBLIC ACT 322 OF 1988.  
COMPLETION: Is voluntary, but is required if eligibility for the AIDS Insurance Assistance Program is desired.

The Department of Social Services will not discriminate against any individual or group because of race, sex, religion, age, national origin, color, marital status, handicap, or political beliefs.

RELEASE OF INFORMATION  
Michigan Department of Social Services

I authorize the Michigan Department of Social Services (MDSS) to receive and disclose medical information related to my HIV infection to MDSS staff as needed to determine my eligibility for the AIDS Insurance Assistance Program.

The information may be used by MDSS to make arrangements for payments on my behalf for health insurance. These arrangements may include contacting my insurance company and/or my place of employment that provided me insurance.

The information may also be disclosed to MDSS staff, or to health care providers as needed to facilitate provision of medical services, medical supplies, or pharmaceuticals.

\_\_\_\_\_  
Applicant's Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Witness's Signature

\_\_\_\_\_  
Date

AIDS INSURANCE ASSISTANCE PROGRAM  
PHYSICIAN ASSESSMENT OF EMPLOYABILITY

1. Patient Name \_\_\_\_\_
2. Social Security # \_\_\_\_\_
3. Nature Of Employment \_\_\_\_\_

4. This person has tested positive for HIV.	Yes	No
	<input type="checkbox"/>	<input type="checkbox"/>

5. It is my judgment that this patient is currently too ill because of HIV related disease to continue working in his/her current job. (If yes, skip #6)	Yes	No
	<input type="checkbox"/>	<input type="checkbox"/>

6. It is my judgment that there is a substantial likelihood that within approximately three months this patient will be too ill because of HIV related disease to continue working in his/her current job.	Yes	No
	<input type="checkbox"/>	<input type="checkbox"/>

REMARKS: Please use additional sheets for additional comments on any of the above items.

7. Physician's Name: \_\_\_\_\_ License Number: \_\_\_\_\_

Address: \_\_\_\_\_

Telephone Number: \_\_\_\_\_

8. Physician's Signature: \_\_\_\_\_

To Examining Physician: You are hereby authorized to release the information requested above to the Department Of Social Services.

9. Patient's Signature: \_\_\_\_\_

<p><b>AUTHORITY:</b> PUBLIC ACT 322 of 1988.</p> <p><b>COMPLETION:</b> Is voluntary, but is required if eligibility for the AIDS Insurance Assistance Program is desired.</p>	<p>The Department of Social Services will not discriminate against any individual or group because of race, sex, religion, age, national origin, color, marital status, handicap, or political beliefs.</p>
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## INSTRUCTIONS FOR COMPLETION OF FORM

It will speed review of your application if you bring this form personally to your physician's office and have him/her complete it while you are there. You should then mail the completed form, along with your Eligibility Form, to the address below.

If this is not possible, the form may be left with your physician for completion later. As soon as the form is completed either you or your physician should submit it to the address below:

AIDS Insurance Assistance Program  
Michigan Plaza Building, N. Tower  
11th Floor, Executive Suite  
1200 Sixth Street  
Detroit, Michigan 48226  
Telephone: (313) 256-1380

AIDS INSURANCE ASSISTANCE PROGRAM: MONTHLY REPORT FORM

THIS FORM IS BEING USED FOR PROGRAM EVALUATION ONLY-NOT FOR ELIGIBILITY

Name \_\_\_\_\_ SSN \_\_\_\_\_ - \_\_\_\_\_ - \_\_\_\_\_ Month \_\_\_\_\_

## PART ONE: Monthly Income Report

	Client	Spouse	Unmarried Children Under 18 at Home
Income From Wages	\$	\$	\$
Income From Rent (Include Room/Board)	\$	\$	\$
Other Income (e.g. Social Security, SSI, Interest Income, Disability, Pension)	\$	\$	\$

## PART TWO: Monthly Report of Assets

	Client	Spouse	Unmarried Children Under 18 at Home
Total value of cash assets at end of month (stocks, bonds, bank accounts, IRA's, CD's, etc.)	\$	\$	\$
Total value of non-cash assets. Exclude your home, household goods, and one vehicle. Include land con- tract, real-estate other than your home, other vehicles, etc.	\$	\$	\$

## PART THREE: Monthly Medical Expenses

EACH TIME MEDICAL EXPENSES ARE INCURRED BY YOU OR YOUR DEPENDENTS COMPLETE ONE LINE OF THIS FORM GIVING ALL REQUESTED INFORMATION. KEEP COPIES OF BILLS OR RECEIPTS FOR ALL MEDICAL EXPENSES, YOUR WORKER NEEDS TO SEE THEM. (CONTINUE ON BACK, IF NEEDED.) NEEDS TO SEE THEM. (CONTINUE ON BACK, IF NEEDED.)

Date	Name of Person Getting Service	Brief Description of Service	Amount of Charge

AUTHORITY: PUBLIC ACT 322 OF 1988

COMPLETION: Is voluntary, but is required  
if eligibility for the AIDS Insurance  
Assistance Program is desired.

The Department of Social Services will not  
discriminate against any individual or group  
because of race, sex, religion, age, national  
origin, color, marital status, handicap, or  
political beliefs.



AIDS INSURANCE ASSISTANCE PROGRAM: MONTHLY REPORT FORM

THIS FORM IS BEING USED FOR PROGRAM EVALUATION ONLY-NOT FOR ELIGIBILITY\*

Name \_\_\_\_\_ SSN \_\_\_\_\_ - \_\_\_\_\_ - \_\_\_\_\_ Month \_\_\_\_\_

Telephone Number \_\_\_\_\_ Do you live with relatives? Yes \_\_\_\_\_ No \_\_\_\_\_

## PART ONE: Monthly Income Report

	Client	Spouse	Unmarried Children Under 18 at Home
Income From Wages	\$	\$	\$
Income From Rent (Include Room/Board)	\$	\$	\$
Other Income (e.g. Social Security, SSI, Interest Income, Disability, Pension)	\$	\$	\$

## PART TWO: Monthly Report of Assets

	Client	Spouse	Unmarried Children Under 18 at Home
Total value of cash assets at end of month (stocks, bonds, bank accounts, IRA's, CD's, etc.)	\$	\$	\$
Total value of non-cash assets. Exclude your home, household goods, and one vehicle. Include land contract, real estate other than your home, other vehicles, etc.	\$	\$	\$

## PART THREE: Monthly Medical Expenses

EACH TIME MEDICAL EXPENSES ARE INCURRED BY YOU OR YOUR DEPENDENTS COMPLETE ONE LINE OF THIS FORM GIVING ALL REQUESTED INFORMATION. KEEP COPIES OF BILLS OR RECIEPTS FOR ALL MEDICAL EXPENSES, YOUR WORKER NEEDS TO SEE THEM. (CONTINUE ON BACK, IF NEEDED.) NEEDS TO SEE THEM. (CONTINUE ON BACK, IF NEEDED.)

Date	Name of Person Getting Service	Brief Description of Service	Amount of Charge

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COMPLETION: Is voluntary, but is required if eligibility for the AIDS Insurance Assistance Program is desired.

The Department of Social Services will not discriminate against any individual or group because of race, sex, religion, age, national origin, color, marital status, handicap, or political beliefs.



Date	Name of Person Getting Service	Brief Description Of Service	Amount of Charge

ATTACHMENT D  
METHODOLOGY FOR DEMONSTRATING  
COST SAVINGS

Due to time constraints we have used a very conservative and simple method of assigning costs based partly on self reporting, and partly on the services uniformly needed by a person with AIDS. While this method does not reflect the true experience of the program, it does demonstrate the substantial cost to benefit ratio that exists.

Each person in the program is required to submit a monthly report form identifying medical services they obtained, and describing their financial status. During the months of November and December we received 29 monthly report forms from 19 people. The cost analysis was performed based on these. A copy of a sample form is attached.

A safe assumption is that if a service is reported, we can be confident it occurred. The array of services identified is too complex to be readily priced. We have therefore ignored any services received other than those identified in the categories below. Excluded services include surgeries, radiology, and home health. Since each person probably was taking retrovir, and requiring lab tests we have assigned a uniform monthly amount for these. The amounts assigned are quite conservative.

The major component of cost savings is inpatient hospital use. The November and December monthly report forms identified four people that had six inpatient hospital stays.

We have assigned costs as follows:

Retrovir: For virtually each eligible we know from direct contact they are taking retrovir. Average Medicaid monthly per person cost for retrovir is \$225.52.

Pentamidine: 13 of 19 eligibles reported they receive pentamidine treatments. Average Medicaid monthly per person cost for pentamidine is \$117.56.

Lab: Cost of lab work is estimated at \$100 per month. This is the cost of basic lab work that should be done each month for a person with AIDS.

Physician services: Each reported physician service was priced based on the Medicaid screen of \$16.60.

Inpatient Hospital: Hospital services are priced based on the typical Medicaid payment per discharge for treatment of AIDS related disease at the hospitals that were identified.

Mr. WAXMAN. Mr. Baird.

#### STATEMENT OF DAVID J. BAIRD

Mr. BAIRD. Mr. Chairman and members of the subcommittee, I want to express my appreciation for inviting us to testify in these important issues.

Besides administering the Insurance Continuation Program in our State, I'm also the Administrator of the Federal Drug Reimbursement Program, and also the targeted AIDS Case Management Program under Medicaid.

I don't want to reiterate too many of the points that Mr. Merwin has already covered and other members of the other panels, but I do want to strongly urge again modifying to allow continuation coverage for any eligible person with health insurance. In our State, 31 percent of the persons under our program have individual coverage, often from self-employment situations.

We also have a high-risk insurance program, and we are currently carrying 6 percent of those on our program as well.

Insurance continuation programs are significant enhancers of the whole AIDS health care delivery system, in our State, certainly. And some of the ways that it does that is that one physician I talked to last week prior to preparing my written comments, mentioned that because of insurance being maintained for over 100 clients on his caseload who have AIDS, he has been able to continue taking Medicaid-eligible clients. He probably carries about 6 percent of the 147 people on our program. He is only four in the same circumstances.

One issue that is important—we have a very expanded program in our State, and what we have tried to do because of the savings we have for those clients who become Medicaid-eligible, we're passing them on kind of as insurance for what is coming up. And in that, what we're trying to do is, by paying the premiums for anyone eligible who has a class 4 diagnosis and who is liable for their insurance premium, is to prevent their loss due to dementia, by being overwhelmed by the disease, and certainly by possible lack of adequate income in the future.

Another way our program works to preserve our health care system is it preserves the Federal drug reimbursement funds that we receive each year now. By keeping people on insurance, we are able to at least continue the costs in that area primarily through the insurance companies.

When I took over administration of the program in May of last year, I was encountering a number of people who had just lost their insurance and were applying for our prescription drug program for AZT reimbursement.

Comments received from clients themselves—one I received last week was startling and it kind of brought things back into perspective, the individual related, you know, the impression I've gotten is that society has kind of turned its back on us. And the message that I received from the program—the Insurance Continuation Program—was a positive one that perhaps society really has not turned its back on us.

If we are to save money and enhance and prolong life for those who are HIV positive, we must use good common sense in designing systems that go beyond our current Medicaid program and which currently requires people to get sick before we start helping them; and that is an issue that has been addressed extensively this morning.

I also believe that the prevention issue, that's kind of been discussed this morning, is extremely important. By giving people something after going through the testing process and the issues that they do through over confidentiality, having a program in place that is going to offer them some monitoring of their immune system as well as AZT and other medications further on down the road, is one that I see starting to pay off in our State. And I think it's one of the most significant prevention issues that we can promote for stopping the spread of this deadly epidemic.

Thank you.

[The prepared statement of Mr. Baird follows:]



KRISTINE M. GEBBIE  
Secretary



STATE OF WASHINGTON  
DEPARTMENT OF HEALTH

Olympia, Washington 98504

Written Testimony presented to Henry A. Waxman, Chairman of the House sub Committee on Health and the Environment and to its members on February 27, 1990

by

David J. Baird, Program Administrator  
HIV/AIDS Insurance Continuation Program  
Washington State Department of Health

Concerning the Washington State HIV/AIDS Insurance Continuation Program

**BACKGROUND**

The concept of the Washington HIV/AIDS Insurance Continuation Program (HICP) was proposed in March 1988 by Ron W. Kero, Director of the Division of Medical Assistance (DMA) of the Department of Social and Health Services (DSHS), Washington's Medicaid agency.

"The program is designed to enable persons with AIDS to continue to work as long as possible and to take maximum advantage of private health insurance coverage. This would minimize dependence on Title XIX medical assistance."

About 40 percent of all AIDS cases in Washington State become eligible for Medicaid. The average annual Washington State Medicaid cost per case averages \$21,732. The 1989-91 biennium cost is an estimated \$19.8 million (\$10.7 million federal share). (From 1/30/90 Office of Analysis and Medical Review Report, Attachment #1.)

The 1989 Legislature enacted legislation that reads as follows:

**"New Section.** Sec. 3 A new sections is added to chapter 70.24 RCW to read as follows:

- (1) Class IV human immunodeficiency virus insurance program, as used in this section, means the program financed by state funds to assure health insurance coverage for individuals with class IV human immunodeficiency virus infection, as defined by the state board of health, who meet eligibility requirements established by the department.
- (2) The department may pay for health insurance coverage with funds appropriated for this purpose on behalf of persons who are infected with class IV human immunodeficiency virus, meet program eligibility requirements, and are eligible for "continuation coverage" as provided by the federal consolidated omnibus budget reconciliation act of 1985 or group health insurance policies:

Written Testimony  
February 27, 1990  
Page 2

PROVIDED, That this authorization to pay for health insurance shall cease on June 30, 1991, as to any coverage not initiated prior to that date."

#### PROGRAM ELIGIBILITY/NO INCOME TEST

The enabling legislation allowed the department to set eligibility requirements via the Washington Administrative Code (WAC), which provides for implementation of legislative action (see attachment #2).

An income test was not included for two reasons:

- "Regardless of a PLWA's (persons living with AIDS) present financial status, it is likely that future earnings and resources will decrease with progression of the disease, leading in some cases to state medical assistance eligibility.
- Indications are that PLWA's will often lose insurance coverage, not just from inability to pay the premiums, but from being overwhelmed by the disease. By paying the premiums directly for such individuals, the state can assure that continuity of coverage is maintained, thus reducing future impact on medical assistance programs and providers." (December 1989 DMA Memorandum).

#### PROGRAM IMPLEMENTATION JUNE - JULY 1989

An initial program description and single page application form were mailed on June 26, 1989 to individuals and organizations most likely to encounter PLWA's with insurance (Physicians, AIDS case managers, community AIDS organizations and hospital social workers), announcing that the processing of applications would begin on July 1, 1989: the date that the newly enacted legislation went into effect.

The first premiums under the new program were paid on July 14, 1989. During July, forty-two applications were received and processed.

#### COST EFFECTIVENESS

In determining cost effectiveness, the following assumptions are applied:

- 40 percent of PLWA's will become eligible for Medicaid. During the period July 1985 through September 1989, 560 Medical-Assistance recipients were treated for AIDS and AIDS-related diseases. That number is 38 percent of the AIDS cases in Washington State, meeting the CDC Surveillance definition as of September 30, 1989.
- Private insurance will cover 80 percent of medical expenses of those PLWA's who have such coverage. Most HMO's cover 100 percent of medical expenses and 16 percent of program applicants are covered under a HMO.

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Based on the above assumptions, cost-effectiveness appears evident.

1. Average cost of insurance premium per month per client is \$138.05.
2. For those premium coverage clients who eventually transition to Medicaid, there will be some additional Medicaid expenses as a result of insurance coverage limitation.
3. Average monthly cost of Medicaid services for PLWA's without additional insurance coverage is \$1,811.00.

#### PROGRAM ADMINISTRATION

The program is jointly administered by the state Medicaid agency, Division of Medical Assistance (DMA), and the state Department of Health (DOH), HIV/AIDS and Infectious Disease Administration.

DMA processes the premium payments, troubleshoots payment problems (often preventing the health insurance policy from expiring due to client non payment) and maintains program payment information.

DOH publicizes the program via a specialized mailing list and brochures and community meetings, formulates program rules, answers questions, and reviews and approves payments.

#### WASHINGTON STATE AIDS DELIVERY SYSTEM

HICP enrollment is enhanced by the existence of a comprehensive state-wide system which includes the state HIV/AIDS program, state and locally funded health departments. These are known collectively as the AIDSNETS. The system is augmented by numerous active private AIDS community organizations.

Washington State's "AIDSNETS" system, created by the Washington Omnibus AIDS legislation of 1988, provides AIDS information/assistance and case management throughout the state. Case managers are familiar with insurance options and, when feasible, actively work with the client to access the HICP. The HIV/AIDS and Infectious Diseases Administration includes information about the program in their brochure "Navigating the Future".

Since payments are made by HICP directly to the employer or insurance company, insurance is not lost for enrolled clients due to lack of payment. Case managers identified loss of insurance due to missed payments as a significant problem prior to HICP. Failure to pay is usually due to cognitive impairment secondary to HIV infection.

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#### OBSERVATIONS

Physicians are motivated to inform clients of the program since insurance reimbursement is higher than Medicaid reimbursement; a significant issue for physicians with large HIV related case loads.

The Washington High-Risk Insurance Pool (HRIP), which is for those who do not and can not obtain insurance, is increasingly being accessed by HIV-positive, asymptomatic, employed individuals who are generally without employer-provided insurance. In addition, persons receiving Social Security income in excess of \$600 a month who face a large and frequently unmanageable "spenddown" are seeking coverage through the HRIP. Many of these persons would not pursue the coverage if Washington State's HIV/AIDS Insurance Continuation Program did not exist.

These disabled clients are strongly motivated to obtain HRIP to preserve income and resources for basic living expenses. With insurance, it is unlikely these client's will need to access state Medicaid services.

Clients often see their private health insurance policy as their last symbol of dignity and independence. These persons may sacrifice basic needs in order to maintain insurance, thus adversely affecting their already poor health. A significant number of early program enrollees mentioned that the HICP's start-up was timely: they were finding it increasingly difficult to make payments. A common belief among those living with AIDS is that "People have turned their backs". "Finding that such a program existed lifted my spirits," related a recent enrollee.

The percentage of PLWA's going on to Medicaid has begun to decrease.

Washington State's AIDS Prescription Drug Program (APDP), funded via the Federal Drug Reimbursement Program, is already preserving funds due to increased accessibility of health insurance for low-income persons, which enables additional PWLA's to access the APDP.

In September 1989, 13 percent of those PLWA's still alive in Washington State were enrolled on HICP. By December 31, 1989, that number had grown to 20 percent.

An average of 26 new clients apply each month. Of the 193 applicants since July 1989, 63 percent are under COBRA, 31 percent have conversion or individual policies, 5 percent are under the state High-Risk Pool and 1 percent have Medicare supplemental insurance.

The oldest applicant is 84 years old and the youngest is 20 years old.

The average premium rate is \$147 a month. HICP currently pays between \$350 and \$500 a month for some clients who have lost their COBRA coverage and subsequently converted to the High-Risk Pool.



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The "Pelosi continuing health coverage legislation, H.R. 2310, which was amended to the budget reconciliation Bill in late 1989", will significantly reduce the average premium over the next 18 months. The legislation extended COBRA coverage for an additional 11 months for those disabled at the time of their qualifying event. The 11 additional months of premium can not exceed 150 percent of the basic premium cost.

#### IN SUMMARY

The reaction to Washington State's HIV/AIDS Insurance Continuation Program has been most positive on the part of beneficiaries and employers. Prior to the advent of HICP, employers out of compassion, were helping former employees pay their health insurance premiums.

The state's largest Health Maintenance Organization, as an employer, sees the program as a positive benefit to former qualified employees.

Insurance companies, in general, have not taken a public position on the program. However, King County Blue Shield, took a negative stance to the program during an newspaper interview in June 1989.

We strongly believe that the Washington State Model of insurance continuation is a cost-effective, positive public program. We strongly urge other interested states to adopt a similar model.

ATTACHMENT NUMBER ONE

Department of Social and Health Services  
Division of Medical Assistance  
Office of Analysis and Medical Review  
January 30, 1980

UTILIZATION OF MEDICAL ASSISTANCE SERVICES  
BY PERSONS WITH AIDS  
JULY 1985 THROUGH SEPTEMBER 1989

During the period July 1985 through September 1989, 800 Medical Assistance recipients were treated for AIDS and AIDS related diseases. Total expenditures for the treatment of these persons was over \$6.8 million.

	FY 1986		FY 1987		FY 1988		FY 1989		INCOMPLETE		TOTAL		STATE SHARE	
	\$	%	\$	%	\$	%	\$	%	\$	%	\$	%	\$	%
<b>TOTAL EXPENDITURES</b>	<b>\$82</b>	<b>100%</b>	<b>\$1,516</b>	<b>100%</b>	<b>\$2,805</b>	<b>100%</b>	<b>\$4,163</b>	<b>100%</b>	<b>\$661</b>	<b>100%</b>	<b>\$3,948</b>	<b>100%</b>	<b>\$4,570</b>	
(000 Omitted)														
Inpatient	\$636	79%	\$1,149	76%	\$1,724	61%	\$2,409	59%	\$254	38%	\$6,171	62%	\$2,897	
Outpatient	\$39	5%	\$73	5%	\$275	10%	\$406	10%	\$91	14%	\$684	9%	\$415	
Physician	\$73	9%	\$145	10%	\$242	9%	\$378	9%	\$70	11%	\$908	9%	\$426	
Drugs	\$16	2%	\$52	3%	\$282	10%	\$590	14%	\$181	27%	\$1,120	11%	\$626	
Other Services *	\$38	5%	\$97	6%	\$282	10%	\$381	9%	\$85	10%	\$664	9%	\$406	
<b>AVERAGE MONTHLY: Persons Receiving Any Care (unduplicated count)</b>	<b>FY 1986</b>		<b>FY 1987</b>		<b>FY 1988</b>		<b>FY 1989</b>		<b>FY 1988</b>		<b>FY 1989</b>			
	33		61		129		183				159			
<b>Average Monthly Users by Type of Care (the same person may be counted in more than one category)</b>														
Inpatient	9		16		25		30				14			
Outpatient	15		29		71		101				89			
Physician	29		51		81		105				123			
Drugs	20		39		94		146				150			
Other Services *	14		31		65		97				75			
<b>Average Monthly Expenditure for Each Person Receiving Care</b>	<b>\$2,056</b>		<b>\$2,077</b>		<b>\$1,611</b>		<b>\$1,900</b>				<b>\$1,043</b>			
<b>Average Annual Expenditure per Person Receiving the Specific Care</b>														
Inpatient	\$6,170		\$6,047		\$6,690		\$6,600				\$4,396			
Outpatient	\$222		\$210		\$322		\$336				\$257			
Physician	\$209		\$236		\$192		\$232				\$257			
Drugs	\$65		\$111		\$251		\$338				\$142			
Other Services *	\$229		\$281		\$348		\$327				\$300			

\* Includes Expenses for Nursing Homes, Durable Medical Equipment, Laboratory - Radiology, Home Health and Ambulance/Required Transportation.

## CLASS IV HIV HEALTH INSURANCE ELIGIBILITY

NEW SECTION

WAC 248-180-010 CLASS IV HUMAN IMMUNODEFICIENCY VIRUS (HIV) INSURANCE-PROGRAM. Definitions of program covered by the department of health.

(1) "Class IV HIV insurance program" means the program authorized by chapter 70.24 RCW and financed by state funds to assure health insurance coverage for an individual with Class IV HIV infection as defined by the state board of health meeting eligibility requirements established by the department.

(2) "Class IV HIV infection" means an illness characterized by the diseases and conditions defined and described by the state board of health in WAC 248-100-011(1) and 248-100-076(1)(c)(i).

NEW SECTION

WAC 248-180-020 ELIGIBILITY. (1) The department shall pay, to the extent a person is liable for group health insurance premiums, such premiums for a person who has a diagnosis of Class IV human immunodeficiency virus (HIV) infection and:

(a) Is terminated from employment for reasons other than gross misconduct;

(b) Has experienced a reduction in employment hours to the extent the applicant is liable for part or all of the health insurance premium;

(c) Is entitled to benefits under Title XVIII of the Social Security Act;

(d) Ceases to be a dependent child under the requirements of the health insurance plan; or

(e) Is divorced or legally separated from the covered employee and has continuation coverage rights.

(2) An applicant's eligibility under the program shall cease when the individual:

(a) Dies;

(b) Loses insurance eligibility for a reason other than the reasons noted under subsection (1) of this section; or

(c) Moves out of state.

Mr. WAXMAN. Thank you very much.

Let me ask this question. Mr. Baird, you indicate that you expect your program is going to save the States and the Federal Government Medicaid dollars. Mr. Merwin is projecting \$2 million in savings in fiscal year 1990. Mr. Baird, you are projecting savings of over \$1,600 per client, per month.

I think the two of you have made a persuasive case, and I know you are going to go see the Congressional Budget Office, and we want that case to be made to them.

But if there are such large savings involved, why aren't other States doing what you're doing? And why should we provide Federal matching funds to encourage States to do what's in their financial interest to do? Your States have already done it without matching Federal funds. How do you respond to that?

Mr. BAIRD. In a sense, I think the answer is thereby encouraging States with the matching dollars, they probably will take a closer look at this whole issue. Other States are looking at it. I have received in the last couple of months six phone calls from States, from Ohio to Arizona, who are very seriously looking at starting similar programs. So I think they are looking at it.

I think perhaps the issue of the Federal matching dollar will be real important. In our State we have a general assistance program that is funded by all State dollars—that is a significant safety net.

So when we are looking our program, we are looking at saving State dollars not just in the Medicaid area but in other areas as well. And other States with similar programs would benefit as well from that.

Mr. WAXMAN. Mr. Merwin, one of the concerns that has been expressed about the Medicaid AIDS legislation is that it would set a bad precedent by limiting benefits to individuals with a particular diagnosis.

As you know, Medicaid currently buys both the low-income elderly and the low-income working disabled into the Medicare program, paying their premiums and cost-sharing. This would be the first buyin limited to individuals with a specific diagnosis.

Did this issue come up in the course of authorizing your program at the State level, and what are your thoughts about that?

Mr. MERWIN. This issue did come up when it was being considered on the State level, and it has come up in direct personal experience I have had with people. I had a woman call me whose husband—she was 30 years old, her husband was sick with cancer, and she expressed some bitterness that if her husband had AIDS there might have been a program that could help him; but because he had cancer, they were in a position of financial ruin.

The reason, notwithstanding that it makes sense to single out the AIDS diagnosis to start with, is that in our State about 10 percent of the general population is Medicaid eligible. We've got almost 50 percent of the AIDS cases that become Medicaid eligible. That's not a statistic that would hold up across all the other diseases.

The other thing about that is that personally I think the power of the idea holds—it is not that it should be restricted to AIDS, it should be used any time it's cost-effective to buy in for medical insurance, I think we should do that.



With AIDS it's very easy to pick this diagnosis out, you know it's going to be cost-effective. When you get into other diseases, for example, like cancer or heart attacks or stroke, the cost of treating that disease isn't necessarily catastrophic.

I think that this question should be looked at very closely. I know at the State level we're going to be looking at it very closely and I would not be surprised to see the idea expanded to include some of the other disease processes.

I know that the State of Ohio is considering putting organ transplants—that's another very clear catastrophic cost for disease process, but it does make sense to have it for people other than AIDS cases.

Mr. WAXMAN. Mr. Baird, do you have any comments on this issue?

Mr. BAIRD. Again, I concur with those comments.

In our State, within our Medicaid program we are paying the health insurance premiums of anyone coming onto Medicaid with health insurance intact as well as the deductibles and the other related expenses.

Mr. WAXMAN. Is that diagnostic-specific or just anyone that's coming on?

Mr. BAIRD. It's anyone coming on, and that's really not the—

Mr. WAXMAN. Is it a medically needy program or is it just anybody—

Mr. BAIRD. It would cover anyone eligible for Medicaid who has insurance.

Mr. WAXMAN. I see.

Mr. BAIRD. But, again, we've taken this a step further. We've been able to, with this small group of people, be able to calculate the savings dramatically. Whether those kinds of savings would hold up again, we would have to look at them kind of for the individual diagnosis. But it certainly has merit.

Mr. WAXMAN. Thank you.

Mr. Dannemeyer.

Mr. DANNEMEYER. Thank you, Mr. Chairman.

Under the Michigan program now, Mr. Merwin, the physician, if they certify that the patient is too ill to work because of AIDS-related diseases, then they are eligible for coverage under that program provided they meet your standards.

You expect, if I understand correctly, that this eligibility will produce about 20 percent of the AIDS cases in your State in the next 20 months.

But now if H.R. 4080 becomes the law and the eligibility standard is changed from full developed AIDS to an HIV carrier is going to substantially increase the percentage of people that would be eligible under your program, wouldn't it?

Mr. MERWIN. Yes. In my written testimony, the third suggestion I made about the Federal laws, it's only cost-effective if the people are incurring lots of medical expenses. And that's why there was consideration of anybody with HIV infection qualifying, we deliberately made the decision, well, that, no, simply having HIV infection didn't necessarily mean you were at risk for losing your insurance. And even if you did, you weren't necessarily incurring high medical costs.

Mr. DANNEMEYER. You've got also the eligibility standards in H.R. 4080 are markedly lower than what pertains in your State. For instance, current law in Michigan, income below 200 percent of Federal poverty standard, and H.R. 4080 says income below 100 percent of Federal poverty line. And assets under Michigan law do not exceed 10,000; under H.R. 4080, assets do not exceed \$4,000. Of course, the big change is under Federal law HIV carriers establishes eligibility and under Michigan law it's fully developed AIDS.

Is it likely that the State of Michigan would adopt the standards adopted in H.R. 4080?

Mr. MERWIN. One of the things I would hope the appreciation for is that the two programs that you've got—Michigan's and Washington's—we aren't very consistent with the Federal guidelines that are being proposed.

So if we were to keep our programs in the form they are in, which I think we would want to do, you've got a situation where we would be using State dollars for some people, Federal dollars for other people, and that's a real administrative complication.

This is the rare program where you want to get more people into it to save more money. I think by having those guidelines too low, you're going to be keeping out people that it would be cost-effective to include.

We would probably keep our program in the form it's at and throw in State dollars for the people that didn't meet the Federal eligibility guidelines I think is what we would do.

Mr. DANNEMEYER. Mr. Baird, you folks in Washington, are the eligibility standards in your program substantially similar to Michigan's?

Mr. BAIRD. We include anyone with a class for AIDS or non-AIDS diagnosis. We have no income or assets limitation.

Mr. DANNEMEYER. I see. But this H.R. 4080 would change all that—HIV carriers?

Mr. BAIRD. Yes, it would indeed do that. Again, it's not cost-effective in many cases. However, the complication of having two different income standards, our single State Medicaid agency—this is a joint administered program, by the way, with our Department of Health and our Medicaid agency. They really want to keep it the way it is with this very liberal stance. It's just going to complicate things for us.

Mr. DANNEMEYER. Your State is one of the States of the Union that has a lower number of AIDS cases than other States; I hope you can keep it that way.

I come back to the point I mentioned at the beginning of this hearing today, it's an amazing process to watch, that here our distinguished chairman, Mr. Waxman, would have five bills—H.R. 3931 to H.R. 3935—that mandates additional coverage for Medicaid to every State in the Union at a time when 49 governors of States have asked the Federal Government to lay off for at least 2 years of new mandates. And yet, my colleague, Mr. Waxman, I'm still waiting for him to suggest to the States of the Union that as a condition of getting any Federal money to deal with AIDS they have to have in place routine steps to control an epidemic, namely, reportability and contact tracing.

As I say, it's an interesting place to work in around here.

Thank you, Mr. Chairman.

Mr. WAXMAN. Let me ask you a question. You decided to cover people who have AIDS but not HIV-infected.

Was that decision made before there were prophylactic early intervention drugs? Did that take that into consideration?

Mr. MERWIN. It was made before that. The cost picture might be different now. But still, the inpatient hospital dollars are what drive the cost analysis, though. So it would be on maybe more cost-effective to start picking up people who are getting drug treatment. That's an open question.

Mr. WAXMAN. Mr. Baird.

Mr. BAIRD. Basically, just to add a little kind of perspective. People who are at risk of losing their insurance are oftentimes are employed or becoming disabled. And those who are HIV-infected and who do have insurance and able to work probably would be able to maintain their insurance. Other parts of the legislation that's being proposed concerning opening it up for the lower income person, that's significant, because perhaps those are under-employed individuals or perhaps temporarily employed, and that's a real significant movement in that direction—I think a real positive one.

Mr. WAXMAN. I want to thank you very much for being here at this hearing today. I think it has been very helpful to us and we look forward to working with you on the legislation.

Mr. MERWIN. Thank you.

Mr. BAIRD. Thank you.

Mr. WAXMAN. That concludes our business for today and we stand adjourned.

[Whereupon, at 1 p.m., the subcommittee was adjourned, to reconvene at the call of the Chair.]

[The following material was submitted:]



American Hospital Association

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Suite 1100  
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Statement  
of the  
American Hospital Association  
for the Record of  
the Subcommittee on Health and the Environment  
Committee on Energy and Commerce  
U.S. House of Representatives  
on  
H.R. 4080, Medicaid AIDS and HIV Amendments of 1990

March 12, 1990

The AIDS epidemic will continue to increase pressures on the health care system during the next decade, exacerbating difficulties in health care access, financing, and delivery. Because Medicaid is a major source of financing care for those with AIDS, improvements in the program are essential if it is to respond effectively to the continuing dilemmas posed by the epidemic. The AHA enthusiastically endorses the efforts of Representative Henry Waxman and his colleagues to ensure that the Medicaid program constructively addresses the problems involved in providing high-quality care to individuals affected by AIDS. H.R. 4080 will take us far in improving Medicaid's response to the AIDS epidemic, ensuring access of poor individuals with AIDS to effective and humane forms of care.

However, the urgent financing issues underscored and exacerbated by the continuing AIDS crisis are neither new nor, unfortunately, confined to a single disease. The health care system already faces severe problems in providing high-quality care to the medically disenfranchised population, and these problems cannot be resolved without addressing the broader issue of inadequate Medicaid reimbursement for all types of care.



Introduction

On behalf of its nearly 5,500 member hospitals, the American Hospital Association (AHA) welcomes this opportunity to provide support for H.R. 4080, the Medicaid AIDS and HIV Amendments of 1990. Hospitals play a key role in the continuum of care for persons with AIDS (PWAs) or other symptoms of HIV infection, and hospitals have expanded services to meet increasing and changing AIDS service needs. The number of hospitals providing hospital-based AIDS services increased nearly 40 percent from 1987 to 1988 alone. In 1988, 59.4 percent of hospitals provided general inpatient care for PWAs, over 2.1 percent had a designated AIDS unit, and over 4.1 percent offered specialized outpatient programs. The role of hospitals in meeting the service needs of PWAs is likely to continue to evolve as the number of diagnosed cases continues to rise and treatment innovations occur.

Mr. Waxman and his colleagues are to be commended for their efforts relating to H.R. 4080. The bill is an important first step in improving care for those with AIDS. The bill is designed to ensure that the Medicaid program responds more effectively to the AIDS epidemic by:

- allowing states to extend Medicaid coverage to include early intervention services for low-income HIV-positive individuals with low immune function;
- requiring states to increase payments for inpatient services given to Medicaid-eligible PWAs by certain hospitals serving a large volume of PWAs;

- authorizing use of federal Medicaid funds to pay premiums for COBRA continuation coverage for low-income individuals who test positive for HIV; and
- permitting states to offer Medicaid coverage for home and community-based services to low-income children diagnosed with AIDS without obtaining a waiver or demonstrating budget neutrality.

Each of these provisions addresses a current inadequacy of the Medicaid program in relation to AIDS services.

#### Optional Coverage of HIV-related Services

Recent research has demonstrated that individuals infected with HIV but not ill enough to meet the Centers for Disease Control (CDC) definition for an AIDS diagnosis can benefit from early diagnostic testing and administration of prophylactic drugs such as aerosolized pentamidine and AZT. The Medicaid program's eligibility policy makes it difficult for individuals infected with HIV to receive these new treatments on a timely basis because most individuals do not become eligible for benefits until they meet CDC's definition for an AIDS diagnosis and thus are classified as disabled. Allowing states to expand Medicaid coverage to include prescribed drugs, physician services, services in various outpatient settings, laboratory services, and case management for low-income HIV-positive individuals with low immune function will mean that low-income patients can obtain these cost-effective services when they are most useful and most likely to prolong and preserve the quality of their lives.

Adjustments in Payments to Certain Hospitals Serving Large Numbers of PWAs

Because Medicaid payment levels in most states fall far below cost, hospitals with large Medicaid populations generally experience substantial payment shortfalls. When added to the increasing burden of uncompensated care that most of these hospitals face each year, these shortfalls jeopardize the survival of those hospitals that serve a disproportionate share of the poor. Hospitals serving a large number of PWAs provide a striking illustration of this problem. Because 40 percent of PWAs eventually become eligible for Medicaid and because AIDS is a particularly expensive disease to treat, Medicaid underfunding seriously undermines the financial stability of hospitals providing care to large numbers of PWAs.

H.R. 4080 would offer some emergency financial relief to some of these providers. To qualify for payment adjustments, hospitals must:

- be Medicaid disproportionate-share hospitals;
- have inpatient admissions for PWAs that, for the most recent year, exceed the lesser of 250 admissions or 20 percent of total admissions; and
- make reasonable efforts to reduce hospitalization of PWAs through cooperative arrangements with at least one outpatient services program.

Adjustments would equal 25 percent of the amount the hospital would otherwise be paid, including its Medicaid disproportionate-share adjustment. States

would have some flexibility to broaden the class of eligible hospitals by lowering the AIDS admission cut-off or to increase the payment adjustments.

The AHA strongly supports any efforts to provide financial relief to distressed hospitals, and the proposed reimbursement adjustment would be a welcome emergency measure for currently stressed hospitals serving a large number of persons with AIDS. In addition, the Committee might want to consider some more direct reimbursement measures to assist these providers, such as elimination of durational limits for PWAs. Another alternative that would help both PWAs and their providers would be to raise medically needy spend-down levels, so that PWAs could be eligible for Medicaid services at an earlier point in their disease. In either case, we strongly urge that Congress assure additional federal dollars, beyond current spending levels, be made available to implement this provision of this legislation. Otherwise, in their efforts to comply with the new requirement, states could be compelled to find money simply by reslicing the Medicaid pie, reducing reimbursement for other services.

As welcome as this provision is, it does not compensate for the overall insufficiency of Medicaid reimbursement for hospital services. In general, Medicaid reimbursement levels fall far below the cost of providing most health care services. These reimbursement shortfalls are particularly pronounced in the case of outpatient care and with regard to resource-intensive services such as trauma and neonatal intensive care, as well as care for PWAs. Although this legislation represents a good first step toward improved reimbursement for a given service, Congress needs to continue to assure that payments for all services come closer to meeting the costs of providing them. Further efforts are necessary to ensure that all Medicaid payments are



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sufficient to guarantee every recipient reasonable access to any necessary hospital treatment in a timely fashion.

COBRA Continuation Coverage Premium Assistance

When PWAs become too sick to work, they often have the option to purchase coverage under their former employer's plan but lack the resources to pay the premiums. Under the Consolidated Omnibus Budget Reconciliation Act of 1985 (COBRA), as amended by the Omnibus Budget Reconciliation Act of 1989, employers with more than 20 employees are required to offer employees who lose their jobs the option of continuing coverage for themselves and their dependents under the employer's group health insurance plan at the employer's group rate. For employees who were disabled at the time of job loss, the employee may continue coverage for up to 29 months. During the first 18 months, the former employee can be charged only 102 percent of the employer's group premium rate; for the remaining months, the maximum premium would be 150 percent of that rate.

While continuing access to group rates can be a very useful benefit, many of those who lose their jobs are unable to take advantage of this provision because they are unable to pay the premiums. H.R. 4080 would authorize the use of federal Medicaid funds to pay the insurance premiums for PWAs who are eligible for continuation coverage under COBRA, have incomes below 100 percent of the federal poverty level (\$5,980 for an individual in 1989), and have countable resources (excluding a home) below a limit of approximately \$8,000.

This provision would benefit PWAs, who would have continued access to private health insurance and thus the resources to protect their already fragile

health conditions. No individual would have to sacrifice basic needs to pay insurance premiums nor be reluctant, as personal resources shrink, to obtain care in a timely and appropriate manner. In addition, having private health insurance contributes to an individual's sense of dignity and independence, which are essential to good health and optimal functioning.

H.R. 4080 would also benefit state Medicaid programs. Without private insurance coverage, individuals must turn to public programs for assistance in meeting health care costs. Using Medicaid funds to pay private insurance premiums would slow the shift of responsibility from the private to the public sector and would help to maintain the stability of a Medicaid program already stretched to its limit to cover current caseloads. The Michigan and Washington state insurance assistance programs clearly indicate that such programs are cost-effective for the Medicaid program. In Michigan, the insurance assistance program saves Medicaid approximately \$3,000 per person per month, and the Washington state program saves almost \$1,700 per person per month.

Given this proven cost-effectiveness and the clear medical benefits to PWAs, we suggest that states be given flexibility in setting the income and resource limits for eligibility under this provision. Under Medicaid's medically needy program, individuals above the poverty level eventually can "spend down" and be eligible for Medicaid. From the state perspective, therefore, it can be cost-effective to continue the private health insurance coverage of these individuals so that all persons who are too ill to work and would eventually have to rely on the Medicaid program to pay for their health care needs would be eligible for this cost-effective option.

Coverage of Home and Community-based Services to Low-Income Children with AIDS

For many children with AIDS, continuous acute care in an inpatient hospital setting is not the treatment of choice. Many children with AIDS could be more appropriately cared for and less expensively in a home or community-based setting with varying levels of medical support and social services, but these services generally cannot be reimbursed through Medicaid. Under current law, states can obtain a waiver to enable them to purchase home and community-based services for those with AIDS who would otherwise have to be cared for in a hospital or nursing home. To obtain such a waiver, states must demonstrate budget neutrality. The administrative complexity of the waiver process and the difficulty of proving that home and community-based services for those with AIDS are budget neutral are disincentives to states to purchase these alternative services under the Medicaid program.

H.R. 4080 would allow states, without a waiver or proof of budget neutrality, to use federal Medicaid dollars for the purchase of home and community-based services for low-income children with AIDS. Services would include case management, supervision or additional services for foster children or their parents, personal care, and respite care. AHA endorses the proposed elimination of disincentives to the purchase of these alternative services which can enhance the quality of life of children with AIDS.

Conclusion

The AIDS epidemic will continue to strain the health care system through the 1990s. If we are to respond compassionately and effectively in caring for those affected, we must improve the ability of the Medicaid program to respond to the crisis. We believe the provisions in H.R. 4080 will take us far in this direction. However, as we grapple with the need to improve care for those with AIDS, we must face the fact that the urgent financing issues exacerbated and underscored by the AIDS epidemic are neither new nor, unfortunately, confined to a single disease. The problems of underinsurance and underfinancing are chronic and cumulative and cannot be resolved without addressing broader financing issues.



ROBERT H. SWEENEY  
President

March 13, 1990

The Honorable Henry Waxman  
Chairman  
Subcommittee on Health and the Environment  
Committee on Energy and Commerce  
2415 Rayburn Building  
U.S. House of Representatives  
Washington, D.C. 20515

Dear Representative Waxman:

I commend you for convening the Subcommittee on Health and the Environment for its February 27 hearing on "The AIDS Epidemic and Medicaid." I would appreciate your including this letter as part of the hearing record.

NACHRI is the only national association of children's hospitals in the United States. Its membership includes 107 institutions in the U.S. as well as Canada. The Children's Hospital of New Jersey, which testified before the Subcommittee on its experience with the care of children with AIDS and HIV infection, is a NACHRI member hospital.

We would like to supplement the testimony of the Children's Hospital of New Jersey with unpublished findings on the experience of 44 other children's hospitals that cared for patients with AIDS according to CDC definition in 1987. These unpublished findings are drawn from the 1987 U.S. Hospitals AIDS Survey which was conducted in conjunction with the National Association of Public Hospitals, with funding from the Robert Wood Johnson Foundation, the U.S. Centers for Disease Control, and the U.S. Department of Health and Human Services Bureau of Maternal and Children Health and Resources Development.

Data were gathered on the care of patients with AIDS from 44 children's hospitals that reported treating at least one child with AIDS in 1987. (The survey did not assess the hospitals' experience with the larger population of patients with HIV infection.) Sixty percent of these children's hospitals also provided data on costs and revenues. The findings below compare the children's hospitals' experience with the care of adult patients with AIDS by other hospitals:

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The National Association of Children's Hospitals and Related Institutions, Inc.  
401 Wythe Street, Alexandria, Virginia 22314  
Phone (703) 684-1355 • FAX (703) 684-1589



The Honorable Henry Waxman  
 March 13, 1990  
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- o Children with AIDS had more frequent admissions, longer lengths of stay, and more total hospital days per year than did adults with AIDS. On average, a child with AIDS had 2.3 admissions per year, an average length of stay of 17 days, and a total of 39.9 days per year in the hospital. Adults had 1.6 admissions per year, and a total of 25.9 days per year in the hospital.
- o Children with AIDS were covered more frequently by Medicaid and less frequently by private insurance than were adults with AIDS. Forty-five percent of children with AIDS received Medicaid assistance and 39% were privately insured. In comparison, 34% of adults with AIDS were assisted by Medicaid and 48% were covered by private insurance.
- o The costs of children's hospitals' inpatient care for children with AIDS were higher than the costs of hospital care for adults with AIDS. The average costs per day for children were 31% higher than for the adult AIDS population responding to the survey, and the annual inpatient costs were two times greater.
- o The financial losses were higher for inpatient children's hospital care for children with AIDS than the costs of adult hospital care for adults with AIDS. About 78% of the costs of care for children with AIDS were reimbursed compared with 86% for adults. On average, a children's hospital experienced an annual loss on inpatient care of children with AIDS of \$7,701, more than five times greater than the losses hospitals incurred on adults patients with AIDS.

These financial data reflect the fact that children with AIDS often require not only longer and more frequent lengths of stay in the hospital but also more intensive clinical care as well as developmental and psychosocial services, assistance with post-hospital placements, and case management.

At the same time, it is important to recognize the limitations of these findings. They relate only to the children's hospitals' financial experience and only to their experience specifically with inpatient care for children with AIDS according to CDC definition. They do not involve the costs of outpatient care, the costs of inpatient and outpatient care of children with HIV infection who are not yet diagnosed with AIDS, and the indirect costs of care hospitals experience when they care for patients with AIDS and HIV infection -- indirect costs resulting from changes in staffing, new employee and community education responsibilities, and new regulatory and safety obligations.

The Honorable Henry Waxman  
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Nor does it include the costs of social services and other home and community-based care.

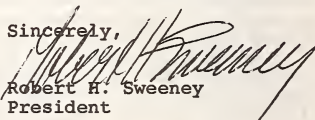
Finally, the survey also does not assess the ability of these hospitals to sustain such financial losses. NACHRI knows from other surveys of its member hospitals that children's hospitals are major providers of care to children of low income families in general. About 85% of children's hospitals qualify as Medicaid "disproportionate share hospitals." While individual children's hospitals, on average, still saw very few cases of children diagnosed with AIDS in 1987, we know from the experience of Children's Hospital of New Jersey and others, that many saw much larger numbers of children with HIV infection. We also know that the numbers of both pediatric AIDS and HIV cases have continued to grow significantly nationwide, with as many as 20,000 projected nationwide by the early 1990s.

In short, the survey results indicate financial difficulties that may be only the tip of the iceberg confronting the delivery of health care and related social services to children with HIV infection and AIDS. Our comparison of them to the costs of care for adults is not to diminish the financial challenges of the delivery care to adults, but rather to emphasize that the challenges for caring for children with AIDS are even greater.

We applaud your efforts to address the financial burden of the selected hospitals that provide most of the care to patients with AIDS through your introduction of H.R. 4080. Because the opportunities for effective treatment are so much greater for children with HIV infection rather than diagnosed AIDS and because the greatest number of HIV infected children are not yet diagnosed with AIDS, we urge you to consider expanding the provision of a state option of home and community based services to children with HIV infection as well as AIDS.

NACHRI also applauds your leadership on behalf of Medicaid reform for all pregnant and women children of low income families. Such reforms in eligibility, enrollment, benefits, and reimbursement, particularly for extraordinarily long stay and high cost cases, are an essential component of an effective federal policy targeted at assisting Medicaid disproportionate share hospitals serving large and growing numbers of children with AIDS and HIV infection.

Sincerely,

  
Robert H. Sweeney  
President

## AIDS ISSUES

### Financing AIDS Early Intervention and Treatment Services

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THURSDAY, APRIL 19, 1990

HOUSE OF REPRESENTATIVES,  
COMMITTEE ON ENERGY AND COMMERCE,  
SUBCOMMITTEE ON HEALTH AND THE ENVIRONMENT,  
*Washington, DC.*

The subcommittee met, pursuant to notice, at 9:28 a.m., in room 2322, Rayburn House Office Building, Hon. Henry A. Waxman (chairman) presiding.

Mr. WAXMAN. The subcommittee will come to order.

Today's hearing is on the financing of AIDS prevention and early intervention.

For the 9 long years of the epidemic, we have worked to provide funding for AIDS research on treatments and cures. No cures have been found, but there have been some very important breakthroughs in treatment. With current knowledge, people whose illness is diagnosed at an early point can postpone their immune deficiency and prevent the pneumonia that is the leading cause of death from AIDS. While such early intervention treatments are expensive drugs, they can forestall or prevent the need for much more expensive hospital care and can allow people with HIV to continue with healthy, productive lives.

This is very good news. It is a promising advance in dealing with AIDS. But it is a real advance in dealing with AIDS only if people can actually get such treatments and the hard fact is that very few people can. Many people do not know that they are infected. Many of those infected did not know that their immune systems are compromised. Many of those who are immune-compromised do not know that there is anything they can do and many of those who know what to do cannot afford to do it.

We are a long, long way from turning the research into progress. The Bush administration has not addressed these issues. While the CDC and the NIH continue to issue statements saying who should be encouraged to be tested and what the state-of-the-art treatment should be, no one in the Public Health Service or the Health Care Financing Administration has proposed funds to implement these statements. Consequently, both prevention and treatment are failing to reach those in need.

The legislation before the subcommittee today would provide assistance in prevention and treatment, preventing infection among

the uninfected, preventing illness among the infected and treating illness among those who are sick. It would provide grants for early intervention and would expand Medicaid to provide such services for poor people before it is too late.

It would assist those high-incidence cities that are becoming overwhelmed with the problems of the epidemic.

We have spent millions of dollars developing research to diagnose and treat AIDS. Hundreds of thousands of our citizens need such a diagnosis and treatment. We should not simply put this research on a shelf, hoping that people will find it and will be able to pay for it themselves.

[Testimony resumes on p. 220.]

[The text of H.R. 4470 follows:]



101ST CONGRESS  
2D SESSION

# H. R. 4470

To amend the Public Health Service Act to establish a program of grants to provide preventive health services with respect to acquired immune deficiency syndrome.

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## IN THE HOUSE OF REPRESENTATIVES

APRIL 4, 1990

Mr. WAXMAN introduced the following bill; which was referred to the Committee on Energy and Commerce

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## A BILL

To amend the Public Health Service Act to establish a program of grants to provide preventive health services with respect to acquired immune deficiency syndrome.

1        *Be it enacted by the Senate and House of Representa-*  
2        *tives of the United States of America in Congress assembled,*

3        **SECTION 1. SHORT TITLE.**

4        This Act may be cited as the "AIDS Prevention Act of  
5        1990".

1 **TITLE I—PREVENTIVE HEALTH**  
2 **SERVICES WITH RESPECT TO**  
3 **ACQUIRED IMMUNE DEFICIEN-**  
4 **CY SYNDROME**

5 **SEC. 101. ESTABLISHMENT OF PROGRAM OF GRANTS.**

6 The Public Health Service Act (42 U.S.C. 201 et seq.)  
7 is amended—

8 (1) by redesignating title XXVI as title XXVII;

9 (2) by redesignating sections 2601 through 2614  
10 as sections 2701 through 2714, respectively; and

11 (3) by inserting after title XXV the following new  
12 title:

13 **“TITLE XXVI—PREVENTIVE HEALTH SERVICES**  
14 **WITH RESPECT TO ACQUIRED IMMUNE DE-**  
15 **FICIENCY SYNDROME**

16 **“PART A—GRANTS FOR PROVISION OF SERVICES**

17 **“SEC. 2601. ESTABLISHMENT OF PROGRAM.**

18 **“(a) ALLOTMENTS FOR STATES.—**For the purposes de-  
19 scribed in subsection (c), the Secretary, acting through the  
20 Director of the Centers for Disease Control, shall for each of  
21 the fiscal years 1991 through 1995 make an allotment for  
22 each State in an amount determined in accordance with sec-  
23 tion 2610. The Secretary shall make payments each such  
24 fiscal year to each State from the allotment for the State if

1 the Secretary approves for the fiscal year involved an appli-  
2 cation submitted by the State pursuant to section 2609.

3       “(b) CATEGORICAL GRANTS.—For the purposes de-  
4 scribed in subsection (c), the Secretary, acting through the  
5 Director of the Centers for Disease Control, may make  
6 grants to entities (including public entities) that—

7           “(1) are grantees pursuant to section 317(j)(2),  
8 section 318(c), section 329, section 330, section 340,  
9 section 509A, or section 1001;

10          “(2) are nonprofit hospitals;

11          “(3) are nonprofit medical facilities that provide,  
12 on an outpatient basis, comprehensive care for individ-  
13 uals infected with the etiologic agent for acquired  
14 immune deficiency syndrome;

15          “(4) have under any appropriations Act received  
16 funds as alternate blood testing sites; or

17          “(5) are comprehensive hemophilia diagnostic and  
18 treatment centers.

19       “(c) PURPOSES OF GRANTS.—

20           “(1) IN GENERAL.—The Secretary may not make  
21 a grant under subsection (a) or (b) unless the applicant  
22 for the grant agrees to expend the grant only for the  
23 purposes of providing, with respect to acquired immune  
24 deficiency syndrome, the preventive health services  
25 specified in paragraph (2). Such services may be pro-

1     vided directly, or through arrangements with public or  
2     nonprofit private entities.

3             “(2) SPECIFICATION OF PREVENTIVE HEALTH  
4     SERVICES.—The preventive health services referred to  
5     in paragraph (1) are—

6             “(A) counseling individuals with respect to  
7             acquired immune deficiency syndrome in accord-  
8             ance with section 2603;

9             “(B) testing individuals with respect to such  
10            syndrome, including tests to confirm that the indi-  
11            viduals are infected with the etiologic agent for  
12            such syndrome, tests to diagnose the extent of the  
13            deficiency in the immune system, and tests to pro-  
14            vide information on appropriate therapeutic meas-  
15            ures for preventing and treating the deterioration  
16            of the immune system and for preventing and  
17            treating conditions arising from the infection; and

18            “(C) providing the therapeutic measures de-  
19            scribed in subparagraph (B).

20            “(d) PREFERENCES IN MAKING CATEGORICAL  
21     GRANTS.—

22            “(1) Subject to paragraph (2), the Secretary shall,  
23            in making grants under subsection (b), give preference  
24            to qualified applicants that will provide preventive



1 health services pursuant to such subsection in any geo-  
2 graphic area for which—

3 “(A) in the case of grants for fiscal year  
4 1991, the number of additional cases of acquired  
5 immune deficiency syndrome, as indicated by the  
6 number of such cases reported to and confirmed  
7 by the Secretary for the most recent fiscal year  
8 for which such data is available, increased signifi-  
9 cantly above the number of additional cases of  
10 such syndrome reported to and confirmed by the  
11 Secretary for the fiscal year immediately preced-  
12 ing such most recent fiscal year; and

13 “(B) in the case of grants for fiscal year  
14 1992 and subsequent fiscal years, the number of  
15 additional cases of infection with the etiologic  
16 agent for acquired immune deficiency syndrome,  
17 as indicated by the number of such cases for the  
18 most recent fiscal year for which such data is  
19 available, increased significantly above the  
20 number of additional cases of such syndrome re-  
21 ported to and confirmed by the Secretary for the  
22 fiscal year immediately preceding such most  
23 recent fiscal year.

24 “(2) With respect to grants under subsection (b)  
25 for fiscal year 1992 and subsequent fiscal years, the

1 Secretary shall, for purposes of preferences under para-  
2 graph (1), apply the criteria described in subparagraph  
3 (A) of such paragraph if the Secretary determines that  
4 sufficient and accurate data are not available for apply-  
5 ing the criteria described in subparagraph (B) of such  
6 paragraph.

7 “(3) In providing preferences under paragraph (1)  
8 for a fiscal year, the Secretary shall give special con-  
9 sideration to rural areas meeting the applicable criteria  
10 established in such paragraph.

11 “SEC. 2602. REQUIREMENTS WITH RESPECT TO CONFIDEN-  
12 TIALITY AND INFORMED CONSENT.

13 “(a) CONFIDENTIALITY.—The Secretary may not make  
14 a grant under section 2601 unless the applicant for the grant  
15 agrees to ensure that information regarding the receipt of  
16 preventive health services pursuant to the grant is confiden-  
17 tial in a manner not inconsistent with applicable law.

18 “(b) INFORMED CONSENT.—

19 “(1) The Secretary may not make a grant under  
20 section 2601 unless the applicant for the grant agrees  
21 that, in conducting testing pursuant to such section,  
22 the applicant will test an individual only after obtaining  
23 from the individual a statement, made in writing and  
24 signed by the individual, declaring that the individual  
25 has undergone the counseling described in section

1       2603(a) and that the decision of the individual with re-  
2       spect to undergoing such testing is voluntarily made.

3       “(2)(A) If, pursuant to section 2608(a), an individ-  
4       ual will undergo testing described in section 2601  
5       through the use of a pseudonym, a grantee under such  
6       section shall be considered to be in compliance with  
7       the agreement entered into pursuant to paragraph (1) if  
8       such individual signs the statement described in such  
9       subsection using the pseudonym.

10       “(B) If, pursuant to section 2608(a), an individual  
11       will undergo testing described in section 2601 without  
12       providing any information relating to the identity of the  
13       individual, a grantee under such section shall be con-  
14       sidered to be in compliance with the agreement entered  
15       into pursuant to paragraph (1) if such individual orally  
16       provides the declaration described in such paragraph.

17   **“SEC. 2603. REQUIREMENT OF PROVISION OF CERTAIN COUN-**  
18       **SELING SERVICES.**

19       “(a) **COUNSELING BEFORE TESTING.**—The Secretary  
20       may not make a grant under section 2601 unless the appli-  
21       cant for the grant agrees that, before testing an individual  
22       pursuant to such section, the applicant will provide to the  
23       individual appropriate counseling with respect to acquired  
24       immune deficiency syndrome (based on the most recently  
25       available scientific data), including—

1           “(1) measures for the prevention of exposure to,  
2           and the transmission of, the etiologic agent for such  
3           syndrome;

4           “(2) the accuracy and reliability of the results of  
5           testing for infection with such etiologic agent;

6           “(3) the significance of the results of such testing,  
7           including the potential for developing acquired immune  
8           deficiency syndrome;

9           “(4) encouraging the individual, as appropriate, to  
10          undergo such testing;

11          “(5) the benefits of such testing, including the  
12          medical benefits of diagnosing the infection in the early  
13          stages and the medical benefits of receiving preventive  
14          health services during such stages;

15          “(6) provisions of law relating to the confidential-  
16          ity of the process of receiving such services, including  
17          information with respect to any disclosures that may be  
18          authorized under applicable law and information with  
19          respect to the availability of anonymous counseling and  
20          testing pursuant to section 2608(a); and

21          “(7) provisions of applicable law relating to dis-  
22          crimination against individuals infected with the etiolo-  
23          gic agent for acquired immune deficiency syndrome.

24          “(b) COUNSELING OF INDIVIDUALS WITH NEGATIVE  
25          TEST RESULTS.—The Secretary may not make a grant



1 under section 2601 unless the applicant for the grant agrees  
2 that, if the results of testing conducted pursuant to such sec-  
3 tion indicate that an individual is not infected with the etiolo-  
4 gic agent for acquired immune deficiency syndrome, the ap-  
5 plicant will review for the individual the information provided  
6 pursuant to subsection (a) with respect to such syndrome,  
7 including—

8 “(1) the information described in paragraphs (1)  
9 through (3) of such subsection; and

10 “(2) the appropriateness of further counseling,  
11 testing, and education of the individual with respect to  
12 such syndrome.

13 “(c) COUNSELING OF INDIVIDUALS WITH POSITIVE  
14 TEST RESULTS.—The Secretary may not make a grant  
15 under section 2601 unless the applicant for the grant agrees  
16 that, if the results of testing conducted pursuant to such sec-  
17 tion indicate that the individual is infected with the etiologic  
18 agent for acquired immune deficiency syndrome, the appli-  
19 cant will provide to the individual appropriate counseling  
20 with respect to such syndrome, including—

21 “(1) reviewing the information described in para-  
22 graphs (1) through (3) of subsection (a);

23 “(2) reviewing the appropriateness of further  
24 counseling, testing, and education of the individual  
25 with respect to such syndrome;

1           “(3) the availability, through the applicant, of pre-  
2       ventive health services;

3           “(4) the availability in the geographic area of ap-  
4       propriate health care, mental health care, and social  
5       and support services;

6           “(5) the benefits of locating and counseling any  
7       individual by whom the infected individual may have  
8       been exposed to such etiologic agent and any individual  
9       whom the infected individual may have exposed to  
10      such agent; and

11          “(6) the availability of the services of public  
12      health authorities with respect to locating and counsel-  
13      ing any individual described in paragraph (5).

14      “(d) COUNSELING OF WOMEN, CHILDREN, AND HEMO-  
15      PHILIACS.—The Secretary may not make a grant under sec-  
16      tion 2601 unless the applicant for the grant agrees that, in  
17      counseling individuals with respect to acquired immune defi-  
18      ciency syndrome pursuant to this section, the applicant will,  
19      where appropriate, provide opportunities for women, chil-  
20      dren, and hemophiliacs to undergo the counseling under con-  
21      ditions appropriate to their needs with respect to the  
22      counseling.

23      “(e) COUNSELING OF EMERGENCY RESPONSE EM-  
24      PLOYEES.—The Secretary may not make a grant under sec-  
25      tion 2601 to a State unless the State agrees that, in counsel-

1 ing individuals with respect to acquired immune deficiency  
2 syndrome pursuant to this section, the State will provide op-  
3 portunities for emergency response employees to undergo the  
4 counseling under conditions appropriate to their needs with  
5 respect to the counseling.

6       “(f) RULE OF CONSTRUCTION WITH RESPECT TO  
7 COUNSELING WITHOUT TESTING.—Agreements entered  
8 into pursuant to subsections (a) through (e) may not be con-  
9 strued to prohibit any grantee under section 2601 from ex-  
10 pending the grant for the purpose of providing counseling  
11 services described in such subsections to an individual who  
12 will not undergo testing described in such section as a result  
13 of the grantee or the individual determining that such testing  
14 of the individual is not appropriate.

15 “SEC. 2604. APPLICABILITY OF REQUIREMENTS WITH RE-  
16               SPECT TO CONFIDENTIALITY, INFORMED CON-  
17               SENT, AND COUNSELING.

18       “The Secretary may not make a grant under section  
19 2601 unless the applicant for the grant agrees that, with re-  
20 spect to testing for infection with the etiologic agent for ac-  
21 quired immune deficiency syndrome, any such testing carried  
22 out by the applicant will, without regard to whether such  
23 testing is carried out with Federal funds, be carried out in  
24 accordance with conditions described in sections 2602 and  
25 2603.

1 "SEC. 2605. REQUIREMENT OF OFFERING AND ENCOURAGING  
2 PREVENTIVE HEALTH SERVICES.

3 "(a) IN GENERAL.—The Secretary may not make a  
4 grant under section 2601 unless the applicant for the grant  
5 agrees that, with respect to preventive health services—

6 "(1) if the applicant is a health provider that reg-  
7 ularly provides treatment for sexually transmitted dis-  
8 eases, the applicant will offer and encourage such serv-  
9 ices with respect to individuals to whom the applicant  
10 provides such treatment;

11 "(2) if the applicant is a health provider that reg-  
12 ularly provides treatment for intravenous substance  
13 abuse, the applicant will offer and encourage such  
14 services with respect to individuals to whom the appli-  
15 cant provides such treatment;

16 "(3) if the applicant is a family planning clinic,  
17 the applicant will, as medically appropriate, offer and  
18 encourage such services with respect to individuals to  
19 whom the applicant provides family planning services;  
20 and

21 "(4) if the applicant is a health care provider that  
22 provides treatment for tuberculosis, the applicant will  
23 offer and encourage such services with respect to indi-  
24 viduals to whom the applicant provides such treatment.

25 "(b) CRITERIA FOR OFFERING AND TESTING.—For  
26 purposes of subsection (a), a grantee to whom such subsection



1 applies is offering and encouraging preventive health services  
2 with respect to the individuals involved if the grantee—

3 “(1) offers such services to the individuals, and  
4 encourages the individuals to receive the services, as a  
5 regular practice in the course of providing the health  
6 services involved; and

7 “(2) provides such services only with the consent  
8 of the individuals.

9 **“SEC. 2606. REQUIREMENT FOR STATE GRANTEEES OF NOTIFI-**  
10 **CATION OF CERTAIN INDIVIDUALS RECEIVING**  
11 **BLOOD TRANSFUSIONS.**

12 “The Secretary may not make a grant under section  
13 2601 to the State unless the State provides assurances satis-  
14 factory to the Secretary that, with respect to individuals in  
15 the State receiving on or after January 1, 1977, a transfu-  
16 sion of any blood product, the State will—

17 “(1) encourage such individuals to receive preven-  
18 tive health services; and

19 “(2) inform such individuals of any public health  
20 facilities in the geographic area involved that provide  
21 such services.

1 "SEC. 2607. REQUIREMENT FOR STATE GRANTEES OF REPORT-  
2 ING AND CONTACT TRACING WITH RESPECT TO  
3 CASES OF INFECTION.

4 "(a) REPORTING.—The Secretary may not make a  
5 grant under section 2601 to a State unless, with respect to  
6 testing for infection with the etiologic agent for acquired  
7 immune deficiency syndrome, the State provides assurances  
8 satisfactory to the Secretary that the State will require that  
9 any entity carrying out such testing confidentially report to  
10 the State public health officer information sufficient—

11 "(1) to perform statistical and epidemiological  
12 analyses of the incidence in the State of cases of such  
13 infection;

14 "(2) to perform statistical and epidemiological  
15 analyses of the demographic characteristics of the pop-  
16 ulation of individuals in the State who have such infec-  
17 tions; and

18 "(3) to assess the adequacy of preventive health  
19 services in the State.

20 "(b) CONTACT TRACING.—The Secretary may not  
21 make a grant under section 2601 to a State unless the State  
22 provides assurances satisfactory to the Secretary that the  
23 State will require that the State public health officer, to the  
24 extent appropriate in the determination of the officer, carry  
25 out a program of contact tracing with respect to cases of

1 infection with the etiologic agent for acquired immune defi-  
2 ciency syndrome.

3 "SEC. 2608. ADDITIONAL REQUIRED AGREEMENTS.

4       “(a) PROVISION OF OPPORTUNITIES FOR ANONYMOUS  
5 COUNSELING AND TESTING.—The Secretary may not make  
6 a grant under section 2601 unless the applicant for the grant  
7 agrees that, to the extent permitted under State law, the  
8 applicant will offer substantial opportunities for an  
9 individual—

10           “(1) to undergo counseling and testing pursuant to  
11       such section without being required to provide any in-  
12       formation relating to the identity of the individual; and  
13           “(2) to undergo such counseling and testing  
14       through the use of a pseudonym.

15       “(b) PROHIBITION AGAINST REQUIRING TESTING AS  
16 CONDITION OF RECEIVING OTHER HEALTH SERVICES.—  
17 The Secretary may not make a grant under section 2601  
18 unless the applicant for the grant agrees that, with respect to  
19 an individual seeking health services from the applicant, the  
20 applicant will not require the individual to undergo testing  
21 described in such section as a condition of receiving the  
22 health services unless such testing is medically indicated in  
23 the provision of the health services sought by the individual.

24       “(c) INCREASED AVAILABILITY OF PREVENTIVE  
25 HEALTH SERVICES.—If an applicant for a grant under sec-

1 tion 2601 has carried out a program of providing any preven-  
2 tive health services during the majority of the 180-day period  
3 preceding the date of the enactment of the AIDS Prevention  
4 Act of 1990, the Secretary may not make an initial grant  
5 under such section unless the applicant for the grant agrees  
6 to expend the grant only for the purpose of significantly in-  
7 creasing the availability of such preventive health services  
8 provided by the applicant above the level of availability pro-  
9 vided under such program during the majority of such period.

10       “(d) ADMINISTRATION OF GRANT.—The Secretary  
11 may not make a grant under section 2601 unless the appli-  
12 cant for the grant agrees that—

13               “(1) the applicant will not expend amounts re-  
14 ceived pursuant to such section for any purpose other  
15 than the purposes described in such section;

16               “(2) if the applicant will routinely impose a  
17 charge for providing the preventive health services de-  
18 scribed in such section, the applicant will not impose  
19 the charge on any individual seeking such services who  
20 is unable to pay the charge;

21               “(3) the applicant will establish such procedures  
22 for fiscal control and fund accounting as may be neces-  
23 sary to ensure proper disbursement and accounting  
24 with respect to the grant; and



1           “(4) the applicant will not expend more than 10  
2       percent of the grant for administrative expenses with  
3       respect to the grant.

4   **“SEC. 2609. REQUIREMENT OF SUBMISSION OF APPLICATION**  
5                   **CONTAINING CERTAIN AGREEMENTS AND**  
6                   **ASSURANCES.**

7       “The Secretary may not make a grant under section  
8   2601 unless—

9           “(1) an application for the grant is submitted to  
10   the Secretary containing agreements and assurances in  
11   accordance with sections 2601 through 2608;

12           “(2) with respect to such agreements, the applica-  
13   tion provides assurances of compliance satisfactory to  
14   the Secretary; and

15           “(3) the application otherwise is in such form, is  
16   made in such manner, and contains such agreements,  
17   assurances, and information as the Secretary deter-  
18   mines to be necessary to carry out this part.

19   **“SEC. 2610. DETERMINATION OF AMOUNT OF ALLOTMENTS**  
20                   **FOR STATES.**

21       “(a) **MINIMUM ALLOTMENT.**—Subject to the extent of  
22   amounts made available in appropriations Acts, the amount  
23   of an allotment under section 2601(a) for a State for a fiscal  
24   year shall be the greater of—

1           “(1) \$300,000 for each of the several States, the  
2       District of Columbia, and the Commonwealth of Puerto  
3       Rico, and \$100,000 for each of the territories of the  
4       United States other than the Commonwealth of Puerto  
5       Rico; and

6           “(2) an amount determined under subsection (b).

7       “(b) DETERMINATION UNDER FORMULA.—The  
8       amount referred to in subsection (a)(2) is the product of—

9           “(1) an amount equal to the amount made avail-  
10      able pursuant to section 2613(b)(1) for the fiscal year  
11      involved; and

12          “(2) a percentage equal to the quotient of—

13           “(A) an amount equal to the population of  
14      the State involved; divided by

15           “(B) an amount equal to the population of  
16      the United States.

17       “(c) DISPOSITION OF CERTAIN FUNDS APPROPRIATED  
18      FOR ALLOTMENTS.—

19          “(1) Amounts described in paragraph (2) shall, in  
20      accordance with paragraph (3), be allotted by the Sec-  
21      retary to States receiving payments under section  
22      2601(a) for the fiscal year (other than any State re-  
23      ferred to in paragraph (2)(C)).

“(2) The amounts referred to in paragraph (1) are any amounts that are not paid to States under section 2601(a) as a result of—

“(A) the failure of any State to submit an application under section 2609;

“(B) the failure, in the determination of the Secretary, of any State to prepare within a reasonable period of time such application in compliance with such section; or

“(C) any State informing the Secretary that the State does not intend to expend the full amount of the allotment made to the State.

“(3) The amount of an allotment under paragraph (1) for a State for a fiscal year shall be an amount equal to the product of—

“(A) an amount equal to the amount described in paragraph (2) for the fiscal year involved; and

“(B) the percentage determined under subsection (b)(2) for the State.

**“SEC. 2611. PROVISION BY SECRETARY OF SUPPLIES AND SERVICES IN LIEU OF GRANT FUNDS.**

“(a) **IN GENERAL.**—Upon the request of a grantee under section 2601, the Secretary may, subject to subsection (b), provide supplies, equipment, and services for the purpose

1 of aiding the grantee in providing preventive health services  
2 described in such section and, for such purpose, may detail to  
3 the grantee any officer or employee of the Department of  
4 Health and Human Services.

5       “(b) **LIMITATION.**—With respect to a request described  
6 in subsection (a), the Secretary shall reduce the amount of  
7 payments under section 2601 to the grantee involved by an  
8 amount equal to the fair market value of any supplies, equip-  
9 ment, or services provided by the Secretary and shall, for the  
10 payment of expenses incurred in complying with such re-  
11 quest, expend the amounts withheld.

12       **“SEC. 2612. EVALUATIONS AND REPORTS.**

13       “(a) **EVALUATIONS.**—The Secretary shall, directly or  
14 through grants and contracts, evaluate programs carried out  
15 with grants made under section 2601.

16       “(b) **REPORT TO CONGRESS.**—The Secretary shall, not  
17 later than 1 year after the date on which amounts are first  
18 appropriated pursuant to section 2613(a), and annually there-  
19 after, submit to the Congress a report summarizing evalua-  
20 tions carried out pursuant to subsection (a) during the preced-  
21 ing fiscal year and making such recommendations for admin-  
22 istrative and legislative initiatives with respect to this title as  
23 the Secretary determines to be appropriate.



1 "SEC. 2613. FUNDING.

2 "(a) AUTHORIZATION OF APPROPRIATIONS.—For the  
3 purpose of making grants under subsections (a) and (b) of  
4 section 2601, there is authorized to be appropriated  
5 \$500,000,000 for each of the fiscal years 1991 through  
6 1995.

7 "(b) ALLOCATION OF FUNDS BY SECRETARY.—

8 "(1) For the purpose of making allotments under  
9 section 2601(a), the Secretary shall make available 50  
10 percent of the amounts appropriated pursuant to sub-  
11 section (a).

12 "(2) For the purpose of making grants under sec-  
13 tion 2601(b), the Secretary shall make available 50  
14 percent of the amounts appropriated pursuant to sub-  
15 section (a).

16 "(c) USE OF FUNDS.—Counseling programs carried out  
17 under this part—

18 "(1) shall not be designed to promote or encour-  
19 age, directly, intravenous drug abuse or sexual activity,  
20 homosexual or heterosexual;

21 "(2) shall be designed to reduce exposure to and  
22 transmission of the etiologic agent for acquired immune  
23 deficiency syndrome by providing accurate information;  
24 and

1           “(3) shall provide information on the health risks  
2           of promiscuous sexual activity and intravenous drug  
3           abuse.”.

## 4           **TITLE II—MEDICAID AIDS AND** 5           **HIV AMENDMENTS**

6           **SEC. 201. OPTIONAL MEDICAID COVERAGE OF HIV-RELATED**  
7                               **SERVICES FOR CERTAIN HIV-POSITIVE INDIV-**  
8                               **VIDUALS.**

9           (a) **COVERAGE AS OPTIONAL, CATEGORICALLY NEEDY**  
10          **GROUP.**—Section 1902(a)(10)(A)(ii) of the Social Security  
11          Act (42 U.S.C. 1396a(a)(10)(A)(ii)) is amended—

12                       (1) by striking “or” at the end of subclause (X),

13                       (2) by adding “or” at the end of subclause (XI),

14          and

15                       (3) by adding at the end the following new sub-  
16          clause:

17                               “(XII) who are described in sub-  
18                               section (s)(1) (relating to certain HIV-  
19                               positive individuals);”.

20          (b) **GROUP AND BENEFIT DESCRIBED.**—Section 1902  
21          of such Act is amended by adding at the end the following  
22          new subsection:

23                       “(s)(1) Individuals described in this paragraph are indi-  
24          viduals not described in subsection (a)(10)(A)(i)—

1           “(A) who have tested positively to be infected  
2       with the HIV virus and to have (as measured through  
3       an appropriate indicator, such ‘as CD4–T4 cell concen-  
4       tration in the blood) an abnormally low immune func-  
5       tion for which medical intervention is indicated to pre-  
6       vent decline in such function or to prevent opportunist-  
7       tic diseases related to AIDS (without regard to wheth-  
8       er or not the individuals display symptoms of AIDS or  
9       opportunistic diseases related to AIDS);

10           “(B) whose income (as determined under the  
11       State plan under this title with respect to disabled indi-  
12       viduals) does not exceed the maximum amount of  
13       income a disabled individual described in subsection  
14       (a)(10)(A)(i) may have and obtain medical assistance  
15       under the plan; and

16           “(C) whose resources (as determined under the  
17       State plan under this title with respect to disabled indi-  
18       viduals) does not exceed the maximum amount of re-  
19       sources a disabled individual described in subsection  
20       (a)(10)(A)(i) may have and obtain medical assistance  
21       under the plan.

22           “(2) For purposes of subsection (a)(10), the term ‘HIV-  
23       related services’ means each of the following services—

24           “(A) prescribed drugs,

1           “(B) physicians’ services and services described in  
2           section 1905(a)(2),

3           “(C) laboratory and X-ray services,

4           “(D) clinic services, and

5           “(E) case management services (as defined in sec-  
6           tion 1915(g)(2)),

7 relating to treatment of infection with the HIV virus or treat-  
8 ment for (or prevention of) opportunistic diseases relating to  
9 AIDS.

10          “(3) In this subsection:

11           “(A) The term ‘AIDS’ means acquired immune  
12           deficiency syndrome.

13           “(B) The term ‘HIV virus’ means the etiologic  
14           agent for AIDS.”.

15          (c) LIMITATION ON BENEFITS.—Section 1902(a)(10) of  
16 such Act is amended, in the matter following subpara-  
17 graph (E)—

18           (1) by striking “and” before “(X)”, and

19           (2) by inserting before the semicolon at the end  
20           the following: “, and (XI) the medical assistance made  
21           available to an individual described in subsection (s)(1)  
22           who is eligible for medical assistance only because of  
23           subparagraph (A)(ii)(XI) shall be limited to medical as-  
24           sistance for HIV-related services (described in subsec-  
25           tion (s)(2))”.



1 (d) CONFORMING EXPANSION OF CASE MANAGEMENT  
2 SERVICES OPTION.—Section 1915(g)(1) of such Act (42  
3 U.S.C. 1396n(g)(1)) is amended by inserting “or to individ-  
4 uals described in section 1902(s)(1)(A)” after “or with  
5 either,”.

6 (e) CONFORMING AMENDMENT.—Section 1905(a) of  
7 such Act (42 U.S.C. 1396d(a)) is amended—

8 (1) by striking “or” at the end of clause (viii),

9 (2) by adding “or” at the end of clause (ix), and

10 (3) by inserting after clause (ix) the following new  
11 clause:

12 “(x) individuals described in section 1902(s)(1),”.

13 (f) EFFECTIVE DATE.—The amendments made by this  
14 section shall apply to medical assistance furnished on or after  
15 January 1, 1991.

16 SEC. 202. PROVIDING FEDERAL MEDICAL ASSISTANCE FOR  
17 PAYMENTS FOR PREMIUMS FOR “COBRA” CON-  
18 TINUATION COVERAGE FOR HIV-POSITIVE  
19 INDIVIDUALS.

20 (a) OPTIONAL PAYMENT OF COBRA PREMIUMS FOR  
21 QUALIFIED COBRA CONTINUATION BENEFICIARIES.—  
22 Section 1902 of the Social Security Act (42 U.S.C. 1396a) is  
23 amended—

24 (1) in subsection (a)(10)—

1 (A) by striking “and” at the end of subpara-  
2 graph (D),

3 (B) by adding “and” at the end of subpara-  
4 graph (E),

5 (C) by inserting after subparagraph (E) the  
6 following new subparagraph:

7 “(F) at the option of a State, for making  
8 medical assistance available for COBRA premi-  
9 ums (as defined in subsection (t)(2)) for qualified  
10 COBRA continuation beneficiaries described in  
11 section 1902(t)(1);”, and

12 (D) in the matter following subparagraph (E),  
13 as amended by section 201(c) of this Act, by  
14 striking “and” before “(XI)” and by inserting  
15 before the semicolon at the end the following: “,  
16 and (XII) the medical assistance made available  
17 to an individual described in subsection (t)(1) who  
18 is eligible for medical assistance only because of  
19 subparagraph (F) shall be limited to medical as-  
20 sistance for COBRA continuation premiums (as  
21 defined in subsection (t)(2))”; and

22 (2) by adding after subsection (s), as added by sec-  
23 tion 201(b), the following new subsection:

24 “(t)(1) Individuals described in this paragraph are  
25 individuals—

1           “(A) who have tested positively to be infected  
2       with the HIV virus (as defined in subsection (s)(3)(B));

3           “(B) who are entitled to elect COBRA continu-  
4       ation coverage (as defined in paragraph (3));

5           “(C) whose income does not exceed the greater  
6       of—

7           “(i) (as determined under section 1612 for  
8       purposes of the supplemental security income pro-  
9       gram) 100 percent of the official poverty line (as  
10      defined by the Office of Management and Budget,  
11      and revised annually in accordance with section  
12      673(2) of the Omnibus Budget Reconciliation Act  
13      of 1981) applicable to a family of the size in-  
14      volved, and

15          “(ii) (as determined under the State plan  
16      under this title with respect to disabled individ-  
17      uals) the maximum amount of income a disabled  
18      individual described in subsection (a)(10)(A)(i) may  
19      have and obtain medical assistance under the  
20      plan; and

21          “(D) whose resources (as determined under sec-  
22      tion 1613 for purposes of the supplemental security  
23      income program) do not exceed twice the maximum  
24      amount of resources that an individual may have and  
25      obtain benefits under that program.

1       “(2) For purposes of subsection (a)(10)(F), the term  
2 ‘COBRA premiums’ means the applicable premium imposed  
3 with respect to COBRA continuation coverage.

4       “(3) In this subsection, the term ‘COBRA continuation  
5 coverage’ means coverage under a group health plan provid-  
6 ed pursuant to title XXII of the Public Health Service Act,  
7 section 4980B of the Internal Revenue Code of 1986, or title  
8 VI of the Employee Retirement Income Security Act of  
9 1974.

10       “(4) Notwithstanding subsection (a)(17), for individuals  
11 described in paragraph (1) who are covered under the State  
12 plan by virtue of subsection (a)(10)(A)(ii)(XI)—

13               “(A) the income standard to be applied is the  
14 income standard described in paragraph (1)(C), and

15               “(B) except as provided in section  
16 1612(b)(4)(B)(ii), costs incurred for medical care or for  
17 any other type of remedial care shall not be taken into  
18 account in determining income.

19 Any different treatment provided under this paragraph for  
20 such individuals shall not, because of subsection (a)(17), re-  
21 quire or permit such treatment for other individuals.”.

22       (b) CONFORMING AMENDMENT.—Clause (x) of section  
23 1905(a) of such Act (42 U.S.C. 1396d(a)), as inserted by sec-  
24 tion 201(d) of this Act, is amended by inserting “or section  
25 1902(t)(1)” after “1902(a)(1)”.



1 (c) **EFFECTIVE DATE.**—The amendments made by this  
2 section shall apply to medical assistance furnished on or after  
3 January 1, 1991.

4 **TITLE III—EMERGENCY RELIEF**  
5 **FOR AREAS WITH SUBSTAN-**  
6 **TIAL NEED FOR SERVICES**

7 **SEC. 301. ESTABLISHMENT OF PROGRAM OF GRANTS.**

8 Title XXVI of the Public Health Service Act, as added  
9 by section 101(3) of this Act, is amended by adding at the  
10 end the following new part:

11 **“PART B—EMERGENCY RELIEF FOR AREAS WITH**  
12 **SUBSTANTIAL NEED FOR SERVICES**

13 **“SEC. 2621. ESTABLISHMENT OF PROGRAM OF GRANTS.**

14 **“The Secretary shall award emergency relief grants for**  
15 **any metropolitan statistical area (as specified by the Secre-**  
16 **tary) that, as of March 31 of the fiscal year preceding the**  
17 **fiscal year for which such a grant is sought for the area, has**  
18 **reported more than 2,000 cases of acquired immune deficien-**  
19 **cy syndrome to the Centers for Disease Control, and that**  
20 **otherwise meets the requirements of this part. (Such a metro-**  
21 **politan statistical area is hereafter in this part referred to as**  
22 **an ‘eligible area’.)**

23 **“SEC. 2622. ADMINISTRATION AND PLANNING COUNCIL.**

24 **“(a) ADMINISTRATION.—**

1           “(1) IN GENERAL.—Assistance made available  
2           under grants awarded under this part shall be directed  
3           to the chief elected official of the city or urban county  
4           that administers the public health agency serving the  
5           greatest proportion of individuals with acquired  
6           immune deficiency syndrome, as reported to the Cen-  
7           ters for Disease Control, in the eligible area for which  
8           such a grant is awarded.

9           “(2) REQUIREMENTS.—

10           “(A) IN GENERAL.—To receive assistance  
11           under paragraph (1), the administering local politi-  
12           cal subdivision shall, subject to subparagraph  
13           (B)—

14           “(i) establish, through intergovernmental  
15           agreement with the chief elected officials  
16           of all local political subdivisions that have in  
17           excess of 10 percent of all individuals with  
18           acquired immune deficiency syndrome, as re-  
19           ported to the Centers for Disease Control, in  
20           such subdivision within the eligible area, an  
21           administrative mechanism to allocate funds  
22           and services based on the proportion of cases  
23           of such syndrome and severity of need of  
24           such subdivisions; and

1                   “(ii) establish a council in accordance  
2                   with subsection (b).

3                   “(B) PRIORITIES.—Allocation of funds and  
4                   services under subparagraph (A) for an eligible  
5                   area shall be made in accordance with the prior-  
6                   ities established, pursuant to paragraph (2)(B) of  
7                   subsection (b), by the council that serves the eligi-  
8                   ble area pursuant to such subsection.

9                   “(b) HIV HEALTH SERVICES PLANNING COUNCIL.—

10                  “(1) IN GENERAL.—To be eligible for assistance  
11                  under this part, the chief elected official described in  
12                  subsection (a)(1) shall agree to provide for an HIV  
13                  health services planning council not later than 30 days  
14                  after the date on which such assistance is first received  
15                  by the official. Such a council shall include representa-  
16                  tives of—

17                  “(A) health care service providers;

18                  “(B) community-based service organizations;

19                  “(C) social service providers;

20                  “(D) mental health providers;

21                  “(E) local public health agencies;

22                  “(F) hospital or health care planning agen-  
23                  cies;

24                  “(G) affected communities; and

25                  “(H) community leaders.

1           “(2) DUTIES.—The planning council provided for  
2           under paragraph (1) shall—

3                   “(A) develop a comprehensive plan for the  
4                   delivery and organization of HIV services pursu-  
5                   ant to section 2621;

6                   “(B) establish priorities for the allocation of  
7                   funds within the eligible area; and

8                   “(C) assess the efficiency of the administra-  
9                   tive mechanism in rapidly allocating funds to the  
10                  areas of greatest need within the eligible area.

11           “(2) METHOD OF PROVIDING FOR COUNCIL.—

12                   “(A) IN GENERAL.—In providing for a coun-  
13                   cil for purposes of paragraph (1), a chief elected  
14                   official receiving a grant under section 2621 may  
15                   establish the council directly or designate an ex-  
16                   isting entity to serve as the council.

17                   “(B) CONSIDERATION REGARDING DESIGNA-  
18                   TION OF COUNCIL.—In making a determination of  
19                   whether to establish or designate a council under  
20                   subparagraph (A), a chief elected official receiving  
21                   a grant under section 2621 shall consider whether  
22                   the purpose of the council can most effectively be  
23                   carried out by designating as the council an exist-  
24                   ing entity that has demonstrated experience in as-  
25                   sessing and planning, within the eligible area,



1 health care service needs regarding acquired  
2 immune deficiency syndrome.

3 “(C) PRIORITY IN DESIGNATIONS.—If a  
4 chief elected official receiving a grant under sec-  
5 tion 2621 makes a determination that, in provid-  
6 ing for a council under paragraph (1), an existing  
7 entity should be designated to serve as the coun-  
8 cil, the chief elected official shall give priority to  
9 designating an entity described in subparagraph  
10 (B).

11 “SEC. 2623. TYPE AND DISTRIBUTION OF GRANTS.

12 “(a) GRANTS BASED ON RELATIVE NEED OF AREA.—

13 “(1) IN GENERAL.—In carrying out section 2621,  
14 the Secretary, acting through the Administrator of the  
15 Health Resources and Services Administration, shall  
16 make a grant for each eligible area under section 2621  
17 for which an application under section 2625 for such a  
18 grant has been approved. Each such grant shall be  
19 made in an amount determined in accordance with  
20 paragraph (3).

21 “(2) EXPENDITURES OF APPROPRIATIONS.—Of  
22 the amounts appropriated under section 2626 for a  
23 fiscal year, the Secretary shall reserve 50 percent for  
24 making grants under paragraph (1). Not later than 90  
25 days after the date on which appropriations under such

1 section are made for a fiscal year, the Secretary shall  
2 obligate all of the amounts so reserved.

3 “(3) AMOUNT OF GRANT.—

4 “(A) Subject to the extent of amounts made  
5 available in appropriations Acts, a grant under  
6 paragraph (1) shall be made in an amount equal  
7 to the amount that bears the same ratio to the  
8 amount reserved under paragraph (2) as the  
9 amount determined under subparagraph (B) bears  
10 to 100.

11 “(B) The amount determined under this sub-  
12 paragraph is the quotient of—

13 “(i) an amount equal to the sum of—

14 “(I) the relative cases per area  
15 factor for such area as multiplied by  
16 three; and

17 “(II) the relative cases per area  
18 factor for such area as multiplied by the  
19 relative per capita factor for such area;  
20 divided by

21 “(ii) four.

22 “(4) RELATIVE CASES PER AREA FACTOR.—As  
23 used in paragraph (3), the term ‘relative cases per area  
24 factor’ means the ratio of the number of individuals  
25 with acquired immune deficiency syndrome in an eligi-

1 ble area for which an application has been submitted  
2 pursuant to section 2625, as reported to the Centers  
3 for Disease Control, to the number of such individuals  
4 in all such eligible areas.

5 “(5) RELATIVE PER CAPITA FACTOR.—As used  
6 in paragraph (3), the term ‘relative per capita factor’  
7 means the ratio of the per capita incidence of individ-  
8 uals with acquired immune deficiency syndrome in an  
9 eligible area for which an application has been submit-  
10 ted pursuant to section 2625, as reported to the Cen-  
11 ters for Disease Control, to the per capita incidence of  
12 such individuals in all such eligible areas.

13 “(6) ADJUSTMENTS.—The Secretary shall make  
14 such proportionate adjustments in amounts allocated  
15 for grants to eligible areas as shall be necessary to  
16 ensure that the total amount of such grants is neither  
17 more or less than the the amount available for grants  
18 under this subsection.

19 “(b) SUPPLEMENTAL GRANTS.—

20 “(1) IN GENERAL.—Not later than 150 days after  
21 the date on which appropriations are made under sec-  
22 tion 2626 for a fiscal year, the Secretary shall obligate  
23 the remainder of the amounts appropriated under such  
24 section for the fiscal year, to make grants under sec-

1       tion 2621 to eligible areas that submit an application  
2       to the Secretary that—

3               “(A) contains a report concerning the dis-  
4       semination of emergency relief funds under sub-  
5       section (a) and the plan for utilization of such  
6       funds;

7               “(B) demonstrates the severe need in such  
8       area for supplemental financial assistance to  
9       combat the HIV epidemic;

10              “(C) demonstrates the commitment of the  
11       local resources of the area, both financial and in-  
12       kind, to combatting the HIV epidemic;

13              “(D) demonstrates the ability of the area to  
14       utilize such supplemental financial resources in a  
15       way that is immediately responsive and cost effec-  
16       tive; and

17              “(E) demonstrates that resources will be al-  
18       located in accordance with the local demographic  
19       incidence of AIDS including funds for services for  
20       infants, children, women, and families with HIV  
21       disease.

22              “(2) AMOUNT OF GRANT.—The amount of each  
23       grant made by the Secretary under paragraph (1) shall  
24       be determined by the Secretary based on the applica-  
25       tion submitted by the eligible area.



1 "SEC. 2624. USE OF AMOUNTS.

2 "(a) IN GENERAL.—A health care provider that re-  
3 ceives assistance under paragraph (1) shall use such amounts  
4 to—

5 "(A) enhance the quality of outpatient and  
6 ambulatory care services provided to low-income  
7 individuals and families with HIV disease;

8 "(B) deliver outpatient and ambulatory care  
9 services including case management to such indi-  
10 viduals and families, including comprehensive  
11 treatment and support services;

12 "(C) prevent unnecessary in-patient hospitali-  
13 zation; and

14 "(D) expedite the provision of services to in-  
15 dividuals in the most medically appropriate level  
16 of service.

17 "(b) ELIGIBLE PROVIDERS.—Amounts received under  
18 a grant awarded under this part may be used by the grantee  
19 to provide direct financial assistance to any public or nonprof-  
20 it private clinic, sub-acute care facility, community health  
21 center, or ambulatory care facility, that demonstrates that  
22 such health care provider—

23 "(A) is providing care or services to a dispro-  
24 portionate share of low-income individuals and  
25 families with HIV disease; and

1           “(B) is expending resources in the provision  
2           of services to such low-income individuals and  
3           families which exceed reimbursement.

4           “(c) PRIORITY.—In allocating assistance received under  
5 a grant awarded under section 2621, the grantee shall give  
6 priority to health care providers eligible under subsection (b)  
7 that—

8           “(A) have established, and agree to imple-  
9           ment, a plan to evaluate the utilization of services  
10          provided in the care of individuals and families  
11          with HIV disease; and

12          “(B) have established a system designed to  
13          ensure that such individuals and families are re-  
14          ferred to the most medically appropriate level of  
15          care as soon as such referral is medically in-  
16          dicated.

17          “(d) ADMINISTRATION AND PLANNING.—Not to exceed  
18 5 percent of amounts received under a grant awarded under  
19 this part may be utilized to carry out the administrative and  
20 planning activities described under section 2622.

21          “SEC. 2625. APPLICATION.

22          “(a) IN GENERAL.—To be eligible to receive a grant  
23 under this part, an eligible area shall prepare and submit, to  
24 the Secretary, an application in such form, and containing

1 such information as the Secretary shall require, including as-  
2 surances adequate to ensure—

3 “(1) that funds received under a grant awarded  
4 under this part will be used to supplement not supplant  
5 State and local funds currently utilized to provide  
6 health and support services to individuals with HIV  
7 disease; and

8 “(2) that agencies and institutions within the eligi-  
9 ble area that will receive funds under a grant provided  
10 under this part shall be participants in an established  
11 HIV community-based continuum of care.

12 “(b) DATE CERTAIN FOR SUBMISSION.—To be eligible  
13 to receive a grant under this part for a fiscal year, an applica-  
14 tion under subsection (a) shall be submitted not later than 45  
15 days after the date on which appropriations are made under  
16 section 2626 for the fiscal year.

17 “(c) ADDITIONAL APPLICATION.—An eligible area that  
18 desires to receive a grant under section 2623(b) shall prepare  
19 and submit, to the Secretary, an additional application at  
20 such time, in such form, and containing such information as  
21 the Secretary shall require, including the information re-  
22 quired under such subsection.

23 “SEC. 2626. AUTHORIZATION OF APPROPRIATIONS.

24 “There are authorized to be appropriated to make  
25 grants under this part, \$300,000,000 in each of the fiscal

1 years 1991 and 1992, and such sums as may be necessary in  
2 each of the fiscal years 1993 through 1995.”.

## 3 **TITLE IV—EMERGENCY** 4 **RESPONSE EMPLOYEES**

### 5 **SEC. 401. ESTABLISHMENT OF PROGRAM.**

6 Title XXVI of the Public Health Service Act, as  
7 amended by section 301 of this Act, is amended by adding at  
8 the end the following new part:

#### 9 **“PART C—EMERGENCY RESPONSE EMPLOYEES**

#### 10 **“Subpart I—Guidelines and Model Curriculum**

#### 11 **“SEC. 2631. GRANTS FOR IMPLEMENTATION.**

12 **“(a) IN GENERAL.—**With respect to the recommenda-  
13 tions contained in the guidelines and the model curriculum  
14 developed under section 253 of Public Law 100–607, the  
15 Secretary shall make grants to States and political subdivi-  
16 sions of States for the purpose of assisting grantees with re-  
17 spect to the initial implementation of such portions of the  
18 recommendations as are applicable to emergency responses  
19 employees.

20 **“(b) REQUIREMENT OF APPLICATION.—**The Secretary  
21 may not make a grant under subsection (a) unless—

22 **“(1)** an application for the grant is submitted to  
23 the Secretary;

24 **“(2)** with respect to carrying out the purpose for  
25 which the grant is to be made, the application provides



1       assurances of compliance satisfactory to the Secretary;  
2       and

3       “(3) the application otherwise is in such form, is  
4       made in such manner, and contains such agreements,  
5       assurances, and information as the Secretary deter-  
6       mines to be necessary to carry out this section.

7       “(c) **AUTHORIZATION OF APPROPRIATIONS.**—For the  
8       purpose of carrying out this section, there is authorized to be  
9       appropriated \$5,000,000 for each of the fiscal years 1991  
10      through 1995.

11     **“Subpart II—Notifications of Possible Exposure Regarding**  
12       **Acquired Immune Deficiency Syndrome and Other In-**  
13       **fectious Diseases**

14     **“SEC. 2641. ESTABLISHMENT OF REQUIREMENT OF NOTIFICA-**  
15       **TIONS WITH RESPECT TO VICTIMS ASSISTED.**

16       **“(a) ROUTINE NOTIFICATION OF DESIGNATED OFFI-**  
17       **CER.—**

18       “(1) If a victim of an emergency is transported by  
19       emergency response employees to a medical facility  
20       and the medical facility makes a determination that the  
21       victim has an infectious disease, the medical facility  
22       shall, with respect to the determination, notify the des-  
23       ignated officer of the emergency response employees  
24       who transported the victim to the medical facility.

1           “(2) If a victim of an emergency is transported by  
2           emergency response employees to a medical facility  
3           and the victim dies at or before reaching the medical  
4           facility, the medical facility ascertaining the cause of  
5           the death of the victim shall, with respect to the desig-  
6           nated officer of the emergency response employees who  
7           transported the victim to the initial medical facility,  
8           notify the designated officer of any determination by  
9           the medical facility that the victim had an infectious  
10          disease.

11           “(3) With respect to a determination described in  
12          paragraph (1) or (2), the notification required in each of  
13          such paragraphs shall be made not later than 48 hours  
14          after the determination is made.

15          “(b) NOTIFICATION UPON REQUEST OF DESIGNATED  
16          OFFICER.—

17           “(1) If a victim of an emergency is transported by  
18          emergency response employees to a medical facility,  
19          the medical facility shall, upon the request of the desig-  
20          nated officer of any emergency response employees  
21          who attended, assisted, or transported the victim,  
22          notify the designated officer of any determination by  
23          the medical facility that the victim has an infectious  
24          disease.

1           “(2) If a victim of an emergency is transported by  
2       emergency response employees to a medical facility  
3       and the victim dies at or before reaching the medical  
4       facility, the medical facility ascertaining the cause of  
5       the death of the victim shall, upon the request of the  
6       designated officer of any emergency response employ-  
7       ees who attended, assisted, or transported the victim,  
8       notify the designated officer of any determination by  
9       the medical facility that the victim had an infectious  
10      disease.

11           “(3)(A) A medical facility shall make a notification  
12      required in paragraph (1) or (2) not later than 48 hours  
13      after receipt of a request pursuant to the paragraph in-  
14      volved if, prior to the request, a determination de-  
15      scribed in such paragraph has been made by the medi-  
16      cal facility.

17           “(B) A medical facility shall make a notification  
18      required in paragraph (1) or (2) not later than 48 hours  
19      after making a determination described in the para-  
20      graph involved if, after receipt of a request pursuant to  
21      such paragraph, the determination is made.

22           “(c) PROCEDURES FOR NOTIFICATION OF DESIGNAT-  
23      ED OFFICER.—

24           “(1) In making a notification required under sub-  
25      section (a) or (b), a medical facility shall provide the

1 date on which the victim of the emergency involved  
2 was transported by emergency response employees to a  
3 medical facility and, upon request, the location at  
4 which such emergency occurred (including, to the  
5 extent practicable, the address of the location).

6 “(2) If a notification under subsection (a) or (b) is  
7 mailed or otherwise indirectly made—

8 “(A) the medical facility sending the notifica-  
9 tion shall, upon sending the notification, inform  
10 the designated officer to whom the notification is  
11 sent of the fact that the notification has been sent;  
12 and

13 “(B) such designated officer shall, not later  
14 than 10 days after being informed by the medical  
15 facility that the notification has been sent, inform  
16 such medical facility whether the designated offi-  
17 cer has received the notification.

18 “(d) DESIGNATION OF INDIVIDUALS TO REQUEST AND  
19 RECEIVE NOTIFICATIONS FROM MEDICAL FACILITIES.—

20 “(1) The public health officer of each State shall,  
21 for the purpose of requesting and receiving notifications  
22 under subsections (a) and (b), and for the purpose of  
23 carrying out subsection (e), designate 1 official or offi-  
24 cer of each employer of emergency response employees  
25 in the State.



1           “(2) In making the designations required in para-  
2 graph (1), a public health officer shall give preference  
3 to individuals who are trained in the provision of  
4 health care or in the control of infectious diseases.

5           “(e) NOTIFICATIONS TO EMPLOYEES.—

6           “(1) After receiving a notification under subsec-  
7 tion (a) or (b), a designated officer of emergency re-  
8 sponse employees shall, to the extent practicable, im-  
9 mediately notify each of such employees who—

10           “(A) responded to the emergency involved;  
11 and

12           “(B) as indicated by appropriate criteria,  
13 may have been exposed to an infectious disease.

14           “(2) A designated officer of emergency response  
15 employees shall, upon request of such an employee—

16           “(A) determine whether, if a victim of an  
17 emergency to which the employee responded had  
18 an infectious disease, the employee might have  
19 been exposed to the disease; and

20           “(B) make a request described in subsection  
21 (b) if, as indicated by a determination made pursu-  
22 ant to subparagraph (A), the employee might have  
23 been exposed to such disease.

1           “(3) A notification under this subsection to an  
2           emergency response employee shall inform the em-  
3           ployee of—

4                   “(A) the fact that the employee may have  
5           been exposed to an infectious disease;

6                   “(B) any action by the employee that, as in-  
7           dicated by appropriate criteria, is medically appro-  
8           priate; and

9                   “(C) if medically appropriate under such cri-  
10          teria, the location of the emergency involved and  
11          the date and time of such emergency.

12          “(f) LIMITATION.—Subsections (a)(1) and (b)(1) shall  
13          not apply to any determination described in such subsections  
14          made with respect to a victim of an emergency after the expi-  
15          ration of the 60-day period beginning on the date that the  
16          victim is transported by emergency response employees to a  
17          medical facility.

18          “SEC. 2642. RULES OF CONSTRUCTION.

19                 “(a) TESTING.—Section 2631 may not, with respect to  
20          victims of emergencies, be construed to authorize or require a  
21          medical facility to test any such victim for any infectious  
22          disease.

23                 “(b) CONFIDENTIALITY.—Section 2631 may not be  
24          construed to authorize or require any medical facility, any  
25          designated officer of emergency response employees, or any

1 such employee, to disclose identifying information with re-  
2 spect to a victim of an emergency.

3 "SEC. 2643. CIVIL MONEY PENALTY AND CIVIL CAUSES OF  
4 ACTION FOR VIOLATION OF PROHIBITION.

5 "(a) ASSESSMENT OF CIVIL MONEY PENALTY.—

6 "(1) Any person who knowingly or negligently  
7 violates section 2641 shall be liable to the United  
8 States for a civil penalty in an amount not to exceed  
9 \$10,000 for each such violation.

10 "(2) A civil penalty under paragraph (1) may be  
11 assessed by the Secretary only by an order made on  
12 the record after opportunity for a hearing in accord-  
13 ance with section 554 of title 5, United States Code.  
14 The Secretary shall provide written notice to the  
15 person who is the subject of the proposed order inform-  
16 ing the person of the opportunity to receive such a  
17 hearing with respect to the proposed order. The hear-  
18 ing may be held only if the person makes a request for  
19 the hearing before the expiration of the 30-day period  
20 beginning on the date such notice is issued.

21 "(3) The Secretary may compromise, modify, or  
22 remit, with or without conditions, any civil penalty as-  
23 sessed pursuant to paragraph (2).

24 "(4) If the Secretary issues an order pursuant to  
25 paragraph (2) after a hearing described in such para-

1 graph, the person who is the subject of the order may,  
2 before the expiration of the 30-day period beginning on  
3 the date the order is issued, seek judicial review of the  
4 order pursuant to section 1331 of title 28, United  
5 States Code, and chapter 7 of title 5, United States  
6 Code.

7 “(5) If a person does not request a hearing pursu-  
8 ant to paragraph (2) and the Secretary issues an order  
9 pursuant to such paragraph, or if a person does not  
10 under paragraph (4) seek judicial review of such an  
11 order, the Secretary may commence a civil action in  
12 any appropriate district court of the United States for  
13 the purpose of recovering the amount assessed and an  
14 amount representing interest at a rate computed in ac-  
15 cordance with section 1961 of title 28, United States  
16 Code. Such interest shall accrue from the expiration of  
17 the 30-day period described in paragraph (4). In such  
18 an action, the decision of the Secretary to issue the  
19 order, and the amount of the penalty assessed by the  
20 Secretary, shall not be subject to review.

21 “(6) The Secretary may not under this subsection  
22 commence proceeding against a person after the expi-  
23 ration of the 5-year period beginning on the date on  
24 which the person allegedly engaged in the violation of  
25 section 2641.



1       “(b) INJUNCTIVE RELIEF.—The Secretary may, in any  
2 court of competent jurisdiction, commence a civil action for  
3 the purpose of obtaining temporary or permanent injunctive  
4 relief with respect to preventing a violation of section 2641.

5       “(c) CIVIL CAUSE OF ACTION BY AGGRIEVED INDI-  
6 VIDUAL.—

7       “(1) Any emergency response employee who is  
8 aggrieved as a result of a violation of section 2641 by  
9 any person (other than a violation of subsection (a)(3),  
10 (b)(3), or (c)(2) of such section) may, in any court of  
11 competent jurisdiction, commence a civil action against  
12 such person to obtain appropriate relief, including  
13 actual and punitive damages and a reasonable attor-  
14 ney’s fee and cost. Such damages shall be not less than  
15 the liquidated amount of \$2,000.

16       “(2) An individual described in paragraph (1) may  
17 not commence proceedings under such paragraph  
18 against a person after the expiration of the 5-year  
19 period beginning on the date on which the person al-  
20 legedly engaged in the violation of section 2641.”.

## TITLE V—HEALTH CARE SERVICES

### SEC. 501. GRANTS FOR DEMONSTRATION PROJECTS FOR COM- PREHENSIVE TREATMENT SERVICES.

(a) IN GENERAL.—The Secretary of Health and Human Services, acting through the Administrator of the Health Resources and Services Administration, may make grants to public and nonprofit entities for the purpose of providing for demonstration projects to provide comprehensive treatment services for individuals infected with the etiologic agent for acquired immune deficiency syndrome.

(b) AUTHORIZATION OF APPROPRIATIONS.—For the purpose of carrying out subsection (a), there are authorized to be appropriated \$30,000,000 for fiscal year 1991, and such sums as may be necessary for each of the fiscal years 1992 through 1995.

### SEC. 502. GRANTS TO STATES FOR PROVISION OF DRUGS FOR TREATMENT.

(a) IN GENERAL.—The Secretary of Health and Human Services, acting through the Administrator of the Health Resources and Services Administration, may make grants to States for the purpose of assisting States—

(1) in purchasing drugs approved by the Commissioner of Food and Drugs for use in the treatment of cases of infection with the etiologic agent for acquired

immune deficiency syndrome (including treating and preventing conditions arising from such infection); and

(2) in distributing such drugs as medically appropriate to indigent individuals in need of the drugs who have no other means by which to acquire the drugs.

(b) AUTHORIZATION OF APPROPRIATIONS.—For the purpose of carrying out subsection (a), there are authorized to be appropriated \$30,000,000 for fiscal year 1991, and such sums as may be necessary for each of the fiscal years 1992 through 1995.

## TITLE VI—CERTAIN DEFINITIONS

### SEC. 601. DEFINITIONS FOR TITLE XXVI OF PUBLIC HEALTH SERVICE ACT.

Title XXVI of the Public Health Service Act, as amended by section 401 of this Act, is amended by adding at the end the following new part:

#### “PART D—GENERAL PROVISIONS

##### “SEC. 2651. DEFINITIONS.

“For purposes of this title:

“(1) The term ‘counseling with respect to acquired immune deficiency syndrome’ means such counseling provided by an individual trained to provide such counseling.

“(2) The term ‘designated officer of emergency response employees’ means an individual designated

1 under section 2641(d) by the public health officer of  
2 the State involved.

3 “(3) The term ‘emergency’ means an emergency  
4 involving injury or illness.

5 “(4) The term ‘emergency response employees’  
6 means firefighters, law enforcement officers, paramed-  
7 ics, and other individuals (including employees of  
8 legally organized and recognized volunteer organiza-  
9 tions, without regard to whether such employees re-  
10 ceive nominal compensation) who, in the course of pro-  
11 fessional duties, respond to emergencies in the geo-  
12 graphic area involved.

13 “(5) The term ‘employer of emergency response  
14 employees’ means an organization that, in the course  
15 of professional duties, responds to emergencies in the  
16 geographic area involved.

17 “(6) The term ‘exposed to the etiologic agent for  
18 acquired immune deficiency syndrome’ means to be in  
19 circumstances in which there is a significant risk of be-  
20 coming infected with such etiologic agent.

21 “(7) The term ‘infection with the etiologic agent  
22 for acquired immune deficiency syndrome’ includes any  
23 condition arising from such etiologic agent.

24 “(8) The term ‘infectious disease’ means hepatitis  
25 B, hepatitis non-A/non-B, pulmonary tuberculosis,



1       meningoccal meningitis, rubella, infection with the  
2       etiologic agent for acquired immune deficiency syn-  
3       drome, and any other disease designated, in accordance  
4       with guidelines issued by the Secretary, as an infec-  
5       tious disease for purposes of part D.

6               “(9) The term ‘person’ includes one or more indi-  
7       viduals, governments (including the Federal Govern-  
8       ment and the governments of the States), governmen-  
9       tal agencies, political subdivisions, labor unions, part-  
10      nerships, associations, corporations, legal representa-  
11      tives, mutual companies, joint-stock companies, trusts,  
12      unincorporated organizations, receivers, trustees, and  
13      trustees in cases under title 11, United States Code.

14              “(10) The term ‘preventive health services’ means  
15      the services specified in section 2601(c)(2).

16              “(11) The term ‘State’ means each of the several  
17      States, the District of Columbia, and the territories of  
18      the United States.

19              “(12) The term ‘territories of the United States’  
20      means each of the Commonwealth of Puerto Rico, the  
21      Virgin Islands, Guam, American Samoa, the Common-  
22      wealth of the Northern Mariana Islands, the Trust  
23      Territory of the Pacific Islands, and any other territory  
24      or possession of the United States.

## 7 TITLE VII—GENERAL PROVISIONS

(a) IN GENERAL.—The Secretary of Health and Human Services, after consultation with the Director of the Office of Rural Health Policy, shall—

(2) in carrying out the study, determine the adequacy in rural areas of services for diagnosing such cases and providing treatment for such cases that are in the early stages of infection.

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tion (a) and submit to the Congress a report describing the findings made as a result of the study.

**SEC. 702. TECHNICAL AND CONFORMING AMENDMENTS.**

The Public Health Service Act (42 U.S.C. 201 et seq.) is amended—

(1) in 406(a)(2), by striking “2101” and inserting “2701”;

(2) in 505(a)(2), by striking “2101” and inserting “2701”;

(3) in section 465(f), by striking “2601” and inserting “2701”;

(4) in section 497, by striking “2601” and inserting “2701”; and

(5) in section 926(b) (as added by section 6103(c)(1) of Public Law 101-239), by striking “2611” and inserting “2711”.

**SEC. 703. EFFECTIVE DATES.**

Part C of title XXVI of the Public Health Service Act (as added by section 101 of this Act) shall take effect on the expiration of the 60-day period beginning on the date of the enactment of this Act. Such title shall otherwise take effect October 1, 1990, or upon the date of the enactment of this Act, whichever occurs later.

Mr. WAXMAN. Before calling on our first witness, I want to recognize my colleague, Mr. Dannemeyer, for any opening statement.

Mr. DANNEMEYER. Thank you, Mr. Chairman, for convening this hearing on H.R. 4470, which would create several new categorical grant programs and a new category of Medicaid eligibility to provide additional Federal assistance to seropositive persons in areas with large case loads of HIV-affected persons.

This hearing comes at a time when many experts—and I use that term advisedly—are telling us that the HIV epidemic has peaked, that we can all breathe a sigh of relief and go home. My friends, this epidemic is not over. These new estimates should not make us complacent, as we will hear from today's distinguished witnesses.

In my opinion, the HIV epidemic remains America's No. 1 public health problem. Anyone who contemplates the significance of what Dr. Gabor Kelen, of the Johns Hopkins University School of Medicine, has found in his ongoing survey of HIV seroprevalence among emergency room patients in innercity Baltimore will understand why we remain concerned.

He has found that the overall HIV seropositivity rate among the predominantly low-income minority patients who use the Johns Hopkins Hospital's emergency room has increased steadily from 3 percent in 1986 to 5.2 percent in 1987, to 6 percent in 1988 and 7.5 percent in 1989. Most of the infected have undiagnosed asymptomatic HIV infection, which means that they are unaware of their infection and presumably take no precautions to protect their loved ones from contracting the HIV virus.

I refer to the HIV epidemic as a public health problem, rather than a civil rights concern. A million or more Americans are infected with this fatal virus, but the vast majority—perhaps as many as 90 percent—do not know that they are infected. Many more Americans have been and continue to be intimate with asymptomatic HIV-infected persons and are unaware of it.

There are many questions we should be asking ourselves with respect to the HIV epidemic. How many of the 90 percent of the infected who are unaware of their situation unwittingly expose their loved ones to this terrible virus? Conversely, how many will return home tonight to an infected spouse or partner with undiagnosed asymptomatic HIV infection and unknowingly become exposed to this virus?

How many couples will decide to have a child, not knowing that the future mother is HIV positive? How many persons would take the necessary steps to prevent transmission of HIV to their loved ones, if only they knew that such a risk existed?

While education remains an essential component of any containment strategy, education alone is not enough. Traditional public health protection must be introduced into the strategy in order to alert the maximum number of infected persons—infected of their risk.

Early detection of the HIV virus continues to be the most important tool in our efforts to control the spread of the epidemic. Early diagnosis enables public health officials, using the tool of confidential reporting, to warn unsuspecting sexual and needle-sharing partners that they have been exposed to a fatal virus.



It allows the infected individual to seek treatment, such as AZT, to alleviate the symptoms that beset the infected and to alert these individuals to new and promising treatments as they become available.

Early diagnosis allows physicians and other health providers to offer the infected patient the best care and counseling at the earliest possible time. Unfortunately, this commonsense approach, the cornerstones of which are reporting positive HIV test results in confidence to public health authorities and the implementation of aggressive partner notification programs, has been ignored by the States with the largest HIV case load.

In fact, fewer than 10 States have adopted a public health approach. Together, they have accounted for a minuscule percentage of the AIDS cases reported to the CDC, less than 5 percent at last count.

Since the House last considered AIDS legislation, which was in September 1988, the organized medical community has slowly but steadily adopted a public health approach to fight the epidemic. Today's hearing will bear witness to that significant and ignored change in the medical community. We will hear from a panel of witnesses representing the State medical societies of Arkansas, New York and Massachusetts.

These distinguished physicians will tell the subcommittee how important it is that we adopt a public health response to the epidemic. In addition, they will comment on H.R. 4470 and highlight the concerns they have with certain of its provisions. I urge my colleagues to listen to their arguments.

We will also hear from the Honorable Joseph Lisa, the chairman of the New York City Council Health Committee. Mr. Lisa, I would like to point out, occupies the same position in the New York City Government that our distinguished colleague, Mr. Waxman, occupies here in Washington. As chairman of the committee, with jurisdiction over this epidemic, he has seen firsthand the terrible consequences AIDS has had in the city where the worst AIDS problem of all, New York City.

Given his position on the front line, it is significant that Mr. Lisa supports a public health approach to control this epidemic. I urge my colleagues to listen to his message and to appreciate what this man has seen.

I would like to include for the record a list of the medical and other organizations that have formally endorsed my legislation, H.R. 3102, the Public Health Response to AIDS Act of 1989.

The response to my bill has been quite gratifying. H.R. 3102 has been endorsed by seven State medical societies representing tens of thousands of concerned physicians.

These societies and their memberships are New York, Massachusetts, New Jersey, Arkansas, West Virginia, Maine and South Dakota. In addition, several national medical specialty societies have formally endorsed H.R. 3102, including orthopedic surgeons, abdominal surgeons, urologists and medical examiners.

Finally, I would like to submit to you a special order that I delivered on the House floor on March 20, 1990, which discusses the significance of the new report on AIDS adopted by the American Medical Association.

In concluding, Mr. Chairman, I apologize for the length of this statement, but there has been a lot of time invested in this effort on both parts and it was interesting for this member to observe that last December, in Hawaii, at the Convention of the American Medical Association, a major change took place with respect to how the official voice of organized medicine treats the AIDS epidemic in America.

When the American Medical Association, under the leadership of one of our witnesses this morning, Dr. Billy Jones, the president-elect of the Arkansas State Medical Society, adopted a resolution which sets the standard that every State in America should adopt confidential reporting and partner notification laws.

That is a major change in the medical profession's view of how this country should be treating the AIDS epidemic and I congratulate the leaders of the American Medical Association and Dr. Jones in particular, for the significant step that was taken.

Thank you.

[The material referred to by Mr. Dannemeyer follows:]

## ENDORSEMENTS FOR H.R. 3102

MEDICAL SOCIETY OF THE STATE OF NEW YORK  
 MASSACHUSETTS MEDICAL SOCIETY  
 MEDICAL SOCIETY OF NEW JERSEY  
 ARKANSAS MEDICAL SOCIETY  
 MAINE MEDICAL ASSOCIATION  
 SOUTH DAKOTA STATE MEDICAL ASSOCIATION  
 WEST VIRGINIA STATE MEDICAL ASSOCIATION  
 NORTH CAROLINA NEUROSURGICAL SOCIETY  
 NEW YORK STATE SOCIETY OF SURGEONS  
 NEW YORK STATE SOCIETY OF OBSTETRICIANS AND GYNECOLOGISTS  
 NEW YORK STATE SOCIETY OF ORTHOPAEDIC SURGEONS  
 STANISLAUS COUNTY MEDICAL SOCIETY (CA)  
 IMPERIAL COUNTY MEDICAL SOCIETY (CA)  
 NATIONAL ASSOCIATION OF MEDICAL EXAMINERS  
 AMERICAN ACADEMY OF ORTHOPAEDIC SURGEONS  
 AMERICAN SOCIETY OF ABDOMINAL SURGEONS  
 AMERICAN UROLOGICAL ASSOCIATION  
 INDEPENDENT DOCTORS OF AMERICA  
 ASSOCIATION OF AMERICAN PHYSICIANS AND SURGEONS  
 AMERICANS FOR A SOUND AIDS POLICY  
 AMERICAN FAMILY ASSOCIATION  
 AMERICAN FEDERATION OF SMALL BUSINESS  
 CONCERNED WOMEN FOR AMERICA  
 CONGRESS OF RACIAL EQUALITY  
 EDWARD R. ANNIS, M.D., PAST-PRESIDENT, AMERICAN MEDICAL ASSOCIATION  
 ROBERT R. REDFIELD, JR., M.D., CHIEF OF RETROVIRAL RESEARCH, U.S. ARMY  
 MARVIN A. SINGLETON, M.D., PRESIDENT, MISSOURI STATE MEDICAL ASSOCIATION  
 FRANK A. ROGERS, M.D., PRESIDENT, INDEPENDENT DOCTORS OF AMERICA



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## House of Representatives

### AMERICAN MEDICAL ASSOCIATION ADOPTS A PUBLIC HEALTH RESPONSE TO THE HIV EPIDEMIC

The SPEAKER pro tempore. Under a previous order of the House, the gentleman from California (Mr. DANNEMEYER) is recognised for 60 minutes.

Mr. DANNEMEYER. Mr. Speaker, today I want to congratulate the American Medical Association for its courageous actions in Honolulu, HI last December, when the overwhelming majority of its members voted to embrace a public health strategy to control the epidemic of HIV infection in America. In particular, I want to salute the physicians who prevailed over elements of the AMA bureaucracy, which wanted to perpetuate organized medicine's reliance on the education only approach to epidemic control. The AMA membership has spoken clearly: it wants physicians and public health officials to treat HIV infection in the same manner as other



sexually transmissible and communicable diseases.

The AMA, in other words, has formally embraced the simple truth that the HIV epidemic is an issue of public health and not one of civil rights.

What exactly does the AMA do in Honolulu, and what does it portend for the future of the epidemic?

The AMA House of Delegates approved an HIV policy update, which contains 108 separate recommendations for Federal, State, and local governments and covers virtually every aspect of the epidemic. The report contains sensible advice for policymakers who want to enact policies to control the epidemic. I would like to draw my colleagues' attention to the following recommendations:

#### THE VALUE OF EARLY DIAGNOSIS OF HIV INFECTION

Recommendation 17-B: That AMA encourage persons who suspect that they have been exposed to HIV to be tested so that appropriate treatment and counseling can begin for those who are seropositive.

AMA argues that "HIV testing accompanied by appropriate counseling can assist in the behavior change process necessary to reduce a patient's risk of infection." The arguments in favor of early diagnosis of HIV infection are even stronger "now that treatments are available." The military experience, moreover, "demonstrates that accurate test results can be achieved in a relatively low prevalence population with relatively low costs of testing and counseling."

This effectively puts to rest the baseless fear that has plagued proposals to offer HIV tests to broad segments of the population; namely that such testing would produce too many "false positive" or "false negative" test results. It is imperative that every at-risk person know his or her serostatus.

#### MANDATORY HIV TESTING IN CERTAIN INSTANCES

The AMA has proposed implementing mandatory HIV testing in certain, carefully defined situations. Again, this sort of proposal was political dynamite only 2 years ago.

Recommendation 19-A: That AMA support mandatory HIV testing of donors of blood and blood fractions, and breast milk; organs and other tissues intended for transplantation; semen or ova for artificial conception; immigrants to the United States; and military personnel.

"Immigrants," the report notes, "have historically undergone a health assessment before admission into the citizenship process. To exclude HIV infection from the health assessment of those seeking United States citizenship would be a change in long-standing U.S. policy and difficult to justify on medical, scientific, or economic grounds."

"Recommendation 20-A: That AMA continue to recommend that testing be mandatory for inmates in federal and state prisons.

In justifying its endorsement of mandatory prison testing, the AMA

explains that "disproportionately high numbers of inmates in specific geographical regions test positive for HIV." But the report goes further, using an argument that, if applied to the rest of society, would require HIV testing of tens of millions of high-risk individuals across America. The report states:

Complete medical care requires knowledge of an inmate's serostatus. As early care provides increasing benefits to those who are HIV infected, the value to inmates of mandatory HIV testing will increase.

Substitute the word "patient" for "inmate" in the above passage and my point is obvious. In fact, the AMA has already accepted this principle for a noninmate population—infants—and in certain specified situations that may arise in hospital settings. "An infant born to a woman who is either thought, or known, to be HIV positive," the report states elsewhere, "should be tested so that appropriate treatment can be initiated immediately." Similarly, the AMA wants hospital medical staffs to develop guidelines "to allow HIV testing of a patient at the physician's discretion without prior consent in cases of puncture injury, or mucosal contact of health caregivers by potentially infected fluids."

#### ROUTINE TESTING IN CLINICAL SETTINGS

As AZT and other AIDS drugs have emerged, organizations and individuals who previously opposed most HIV testing, such as the AMA, have slowly but steadily come to accept the wisdom of early diagnosis of HIV infection through widespread routine testing programs. Indeed, the AMA report states that "HIV testing has become the gateway to early care."

And, quite apart from the availability of AZT and other therapeutic drugs, quality medical care requires that physicians know their patient's serostatus in order to "reduce the likelihood that an HIV infection will be inadvertently exacerbated by other treatments or conditions." This last argument has been viable since the onset of HIV testing; it is unfortunate that we have had to wait so long for it to be recognized.

AMA also recognizes the crucial link between widespread routine testing and partner notification programs. The report emphasizes that:

There are still individuals who need to know their serostatus to help them act responsibly. There are still those who will not suspect infection unless a seropositive sexual or needle sharing partner tests HIV positive and discloses this information to them.

Thus, the AMA recommendation with respect to voluntary testing is entirely consistent with the provisions in my own legislation, H.R. 3102, the Public Health Response to AIDS Act. According to the AMA, persons in the following categories should be offered and encouraged to undergo HIV testing:

Patients in clinics for sexually transmitted disease, drug abuse, family planning, and tuberculosis; the newborns of women who are or might be infected, as indicated by the mother's sexual or drug history and/or considering the prevalence of HIV infection in the local community; and hospital patients who require surgical or other invasive procedures, taking into account the prevalence of HIV infection in the local community.

Reflecting the growing concern that the epidemic is spreading out of control in certain urban areas, the AMA recommendation includes a warning that, if voluntary HIV testing is not sufficiently accepted, "the hospital and medical staff may consider requiring HIV testing." Again, this is a major philosophical change among organizations which have opposed most testing in the past.

#### HIV TEST CONSENT

The AMA has also adopted a wise policy with respect to the consent required from patients tested for HIV infection. Historically, physicians have sought to obtain a knowing commitment from the patient, which usually requires nothing more elaborate than the patient's verbal consent, but occasionally demands something more concrete, such as a written acknowledgment from the patient. To require that patients give their written consent in every instance, however, goes too far, and may prove unduly burdensome to harried physicians who seek to provide top quality care in crowded and less than ideal settings.

Thus, AMA advocates a consent procedure "that is appropriate to the setting and is the least burdensome to the person being tested, as well as those responsible for testing." This requires an approach that maintains the option for either written or verbal consent. The report notes:

In some circumstances a written consent will be appropriate, but in other situations a verbal consent will be adequate. Similarly, in some settings a lengthy form is appropriate, while in others a very brief acknowledgment will be sufficient.

The most desirable solution, I believe, would allow the physician to make the determination with respect to the consent procedure that best suits the medical needs of the patient being tested.

#### CONFIDENTIAL REPORTING AND PARTNER NOTIFICATION

In a departure from the usual even-handed and clinical tone of the recommendations, the delegates adopted forceful language to express their support of reporting HIV test results in confidence to public health officials and the implementation of partner notification programs in every community.

In a near unanimous demonstration of support, the AMA House of Delegates adopted the following resolutions:

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**Recommendation 27-A.** That the AMA strongly recommends a system for contact tracing and partner notification for unsuspecting sexual or needle-sharing partners who might have been HIV-infected should be established in each community.

**Recommendation 27-E.** That the AMA strongly recommends the reportability of HIV seropositive patients to the Department of Health of the 50 States for the purposes of contact tracing and partner notification.

With the adoption of these resolutions, the AMA is now foursquare behind a public health response to this epidemic. These resolutions reflect what every pool of physicians and other health care providers has shown; namely, that the vast majority of physicians supports treating HIV infection in the same manner as other sexually transmissible diseases.

Why are partner notification programs so important that the AMA would "strongly" recommend that they be established in "each community" in America?

Under a partner notification program, every person who is contacted, infected or not, has been intimate with someone who is carrying a fatal virus. Those who are HIV-negative will understand that they have had a close brush with mortality and will be more likely to change their behavior in the future. For these individuals, the counseling and education that follows will be more meaningful and effective than if it had been offered to them in a vacuum. HIV counseling and education, in other words, must be offered where possible in the context of a partner notification program. Of course, seropositive individuals who are contacted have the opportunity to receive available treatments to prevent the onset of associated infections and to change their behavior to prevent further transmission of the virus to loved ones.

Why is HIV reporting so crucial that the AMA would urge all 50 States to adopt it?

First, confidential reporting is essential to the success of partner notification programs because public health workers must be able to locate infected individuals who refuse to voluntarily inform their contacts of their risk. For example, one study found that, 12 months after being notified that they were seropositive, only 64 percent of blood donors had voluntarily revealed their test results to their primary sexual partners. Under a system with identity-linked reporting, the sexual contacts of these recalcitrant donors would be able to learn of their risk and take appropriate steps to obtain available treatments and prevent further transmission.

Second, reporting enables public health officials to learn the extent of infection in their communities, and to better assess the efficacy of control programs. Annual group specific incidence rates can be tracked only through a confidential reporting system that collects unduplicated test

results by name or other identifying data.

Third, reporting permits health officials to provide follow up counseling to tested individuals who fail to return for counseling.

Fourth, a reporting system would enable health providers to recall (a) seropositive individuals for effective antiretrovirals that may subsequently be developed, and (b) seronegative individuals for retesting and administration of protective vaccines.

Fifth, reporting allows for the implementation of restrictive measures against sociopathic individuals who knowingly attempt to spread the virus to others. This is consistent with AMA recommendation 28, which endorses the imposition of sanctions against those who knowingly and willingly place unsuspecting persons at risk of infection.

#### WHY THE AMA ADOPTED A PUBLIC HEALTH RESPONSE TO THE EPIDEMIC

I have attached a copy of a remarkable firsthand account of the AMA's recent interim meeting in Honolulu written by the president-elect of the Arkansas Medical Society, William N. Jones, M.D. Dr. Jones fought doggedly for almost a year to convince the AMA leadership to place the questions of reportability and partner notification before the AMA House of Delegates. In order to prevail, Dr. Jones had to overcome the AMA staff's subtle, but pervasive, pressure against these initiatives.

Last June, at the AMA's annual meeting in Chicago, Dr. Jones spoke before the AMA's Reference Committee in support of a resolution introduced by the Medical Society of the State of New York. The New York physicians wanted the AMA to take the position that AIDS is a communicable and sexually transmissible disease, and that States should apply the same public health measures to contain the HIV epidemic as they have applied to control the spread of other communicable diseases. This straightforward principle has formed the basis of the New York society's lawsuit against Gov. Mario Cuomo. Unfortunately, the AMA leadership voted to postpone consideration of these issues until the interim meeting in December.

When the AMA reconvened in December, the delegates were presented with a report that was inadequate in at least two important areas. Dr. Jones complained that:

Its statement on contact tracing and partner notification was weak and there was no consideration, pro or con, on reportability of HIV sero-positivity.

The report merely directed the AMA to "urge all communities to consider implementing" contact tracing and partner notification programs. Jones and other physicians wanted to strengthen the language, noting that "the words 'urge to consider' were not strong enough direction." Addressing

the hundreds of assembled delegates, Jones said:

There is one glaring deficiency in this report. It fails to recognize the need for reporting HIV sero-positive persons to the health departments of the 50 states. . . If we do not require the reporting of HIV sero-positive individuals, there is no way for an adequate contact tracing and partner notification program to be carried out and have a positive effect on slowing the spread of the epidemic.

It is past time for the AMA to take a firm position of leadership and emphatically state the importance of HIV sero-positivity reportability and individual contact tracing. Everyone in this room must know by now and understand that HIV infection is a continuum of disease. To endorse reporting of AIDS cases and not HIV infection is inconsistent policy.

The delegates responded with a show of vocal support that "was greater in volume than the summation of all the applause other issues had received since we began deliberating that morning." Unfortunately, the advocates of a civil rights response continued to stonewall the issue. It took another 24 hours of behind-the-scenes maneuvering to secure the support of senior AMA officials. But, when the AMA establishment finally relented, the subsequent outpouring of support overwhelmed Jones and his allies. He described the scene:

I was pleased with the enthusiasm and the volume of applause that followed. Immediately, endorsement came from the delegations from Mississippi, New York, Virginia, West Virginia, Florida, and the delegate from the American Academy of Dermatology. Opposition was basically from California and . . . the United States Public Health Service spokesman was negative in his remarks.

In the end, there "was no audible opposition" to the voice vote on the two amendments. At long last, the forces of public health had won.

In closing, I would like to comment briefly on the actions of the official representative of the U.S. Public Health Service at the AMA meeting. The official position of the Public Health Service was set forth in the July 21, 1989 issue of the *Mortality and Morbidity Weekly Report*, which includes a report that recommends confidential HIV reporting to the States.

Since receiving Dr. Jones' account of the meeting, I have sent a letter to Assistant Secretary James Mason requesting that he conduct an inquiry into this situation. The observations of Dr. Jones and other suggest that, in opposing the resolutions on reporting and partner notification, this individual deliberately misrepresented the position of the Public Health Service to the hundreds of AMA delegates in Honolulu.

For the record, I have also attached by letter to Dr. Mason, which describes my concerns.

#### CONCLUSION

Soon, the Subcommittee on Health will once again consider an omnibus



AIDS bill. Although it is uncertain at this time, we expect the package will include legislation addressing HIV testing, confidentiality, and counseling issues in addition to a proposal to expand the Medicaid Program to make asymptomatic HIV infection a new category of eligibility for infected individuals who otherwise satisfy the income requirements of State Medicaid programs.

The significance of the AMA's actions in Honolulu to the legislative struggles that lie ahead cannot be overestimated. I welcome the voice of organized medicine in America to the side of public health and I pray that the Congress will soon adopt a responsible approach to control this tragic epidemic.

Mr. Speaker, the doctor in America who deserves the credit in my judgment for bringing the AMA to the point where they changed their position last December is Dr. Billy Jones of the State of Arkansas, the president-elect of the Arkansas State Medical Society. He has written a fine article entitled, "The System Works if You Are Willing To Work the System," and I will attach this article by Dr. Jones from Little Rock, AR, along with a copy of a letter that I have written to Dr. James Mason on March 5 as a part of my record in this special order on this day.

#### THE SYSTEM WORKS IF YOU ARE WILLING TO WORK THE SYSTEM

(By William N. Jones, M.D., President-Elect, Arkansas Medical Society, Chairman, Committee on AIDS)

(All of us who have taken on the responsibility of leadership from time to time have been critical about some aspect of the AMA and AMS. It behooves us to change what we perceive as wrong or poor policy because, like it or not, Congress and our state legislature look to those bodies for advice and direction in matters that concern the public health and how medicine is, and will be, practiced.)

I attended the 138 Annual Meeting of the American Medical Association in Chicago, June 18-22, 1989. Since it was my first experience at that level of organized medicine, I was excited and at the same time somewhat in awe of the proceedings. I attended as the President-Elect of the Arkansas Medical Society so I could become informed about the issues and concerns of organized medicine and be aware of the leadership's approaches to those problems.

Any member of the AMA may attend the Annual and Interim Meetings and address any item of business to come before the House of Delegates. The forum that allows this is the reference committee. Every report or resolution to ultimately be considered by the House of Delegates is first discussed in a reference committee.

The agenda of the House of Delegates included many resolutions pertaining to Human Immunodeficiency Virus (HIV). At the annual session of the Arkansas Medical Society, the AMS House of Delegates endorsed a resolution previously adopted by the Medical Society of the State of New York which declared that the AMA House of Delegates should formally take the position that AIDS is a communicable/sexually transmissible disease and that states should apply the same public health measures to

contain the HIV epidemic as are taken to control the spread of other communicable/sexually transmissible diseases. Appropriate notification of the AMS endorsement was sent to the AMA, the Medical Society of the State of New York and our senators and congressmen.

In Chicago at the June meeting, I spoke in Reference Committee E in support of the New York Resolution. I also pleaded with the reference committee to recommend to the House of Delegates the endorsement of reportability of HIV sero-positivity for the purpose of contact tracing and partner notification, important measures to take to slow the spread of the HIV epidemic. The opposition which included the Surgeon General of the United States and civil libertarians, true to form, stated that such policies would lead to breach of privacy and confidentiality of the infected index person. Additional arguments raised suggested that since there was no effective treatment there was nothing to be offered the person found to be HIV infected, that such a program would lead to decrease in volunteer testing and would not be cost effective.

In rebuttal, I told the reference committee that the purpose of those time proven strategies was to make it possible for the infected person to be counseled on all aspects of the infection and the determination of his or her sexual and drug contacts so they might be interviewed, counseled and offered testing. The process known as contact tracing has been an historically proven technique for the control of sexually transmitted diseases for over 40 years and in large measure contributed to the control of syphilis and gonorrhea.

Regarding privacy and confidentiality of the infected index person, one should also consider the right of the previously uninformed contact. The rights of the individual to privacy and confidentiality are protected in any sexually transmitted disease program, however, the bottom line is that individual rights have to be second consideration to the rights of the public to be protected from the spread of this fatal viral epidemic.

For more than two years we heard anecdotal stories and information from experienced therapists of HIV disease that AZT lengthened the interval between infection and clinical disease. Published peer reviewed articles now have established this as fact.

In states where reporting of HIV sero-positive status is law or regulation, such as Arkansas and Colorado, volunteer testing has not been affected.

Ten resolutions pertaining to AIDS issues were debated in Reference Committee E. Subsequently the House of Delegates instructed the Board of Trustees to consider those resolutions while it updated the AMA Policy on AIDS—Report YY (1987)—and report back at the Interim Meeting in December 1989. This resulted in Report X (1-89) of the Board of Trustees—AMA HIV Policy Update as prepared by members of the staff of the AMA and the Council on Scientific Affairs.

Report X was a significant improvement in the 1987 AMA AIDS Policy but it was, I felt, inadequate in at least two major areas. Its statement on contact tracing and partner notification was weak and there was no consideration, pro or con, on reportability of HIV sero-positivity.

The Interim Meeting of the AMA House of Delegates was held in Honolulu, December 3-6, 1989. The various reference committees began their deliberations on the morning of December 4. I attended Reference Committee E which had received Report X for discussion.

Just before the committee was called to order, I renewed acquaintance with Drs. Brian and Lawrence McNamee. These brothers have degrees in medicine and law and have published a book and several articles on AIDS issues. We discussed various deficiencies in Report X and how we might work to correct them. I suggested that we sit in different areas of the room and speak from each of the three microphones to create the appearance of general support for our points of view. Although the dress of the meeting was casual, we all wore dark suits and red ties. I also recommended that we allow the opposing viewpoint to be expressed first so we could both rebut and make our points in the middle and end of discussions. We also agreed not to speak too often in order to be listened to when we wanted to suggest a significant change in the document.

Report X of the Board of Trustees—AMA Policy Update—was 25 pages long and included 35 major recommendations, each of which had subparts A, B, C, etc. Each recommendation was discussed pro and con starting about 9:30 in the morning and continuing for the next five hours. Although I had much interest in the early discussions, I deliberately waited for the subject of contact tracing and partner notification on page 21.

Recommendation 29A stated, "That AMA urge all communities to consider implementing a contact tracing and partner notification program to warn unsuspecting sexual or needle-sharing partners, who might have become HIV infected."

Although I was pleased the report addressed contact tracing and partner notification, I was not pleased with the wording of the recommendation. I felt the words "urge to consider" were not strong enough direction.

The same old arguments in opposition to contact tracing and partner notification that had been raised in Chicago were again stated by persons of civil libertarian orientation and by representatives of the United States Public Health Service (USPHS).

I then addressed the committee as follows:

"Mr. Chairman: We have been debating particulars of this proposed policy for ours but there is one glaring deficiency in this report. It fails to recognize the need for reporting HIV sero-positive persons to the health departments of the 50 states. I rise to request the AMA Board of Trustees Report X be modified to include a section supporting the requirement of reporting HIV sero-positive persons. If we do not require the reporting of HIV sero-positive individuals, there is no way for an adequate contact tracing and partner notification program to be carried out and have a positive effect on slowing the spread of the epidemic."

"It is past time for the AMA to take a firm positive of leadership and emphatically state the importance of HIV sero-positivity reportability and individual contact tracing. Everyone in this room must know by now and understand that HIV infection is a continuum of disease. To endorse reporting of AIDS cases and not HIV infection is inconsistent policy."

"The rights of the individual to privacy and confidentiality have to be second consideration to the right of the public to be protected from this fatal viral epidemic."

The subsequent applause, both hand clapping and verbal, was overwhelming! But that did not deter further comment against this point of view from several persons including a member of USPHS and Dr. Lonnie Bristow, representing the AMA Board of Trustees. Among other things, he said that

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the trustees had considered this point and they felt it was not a timely recommendation.

INTRODUCED BY THE ARKANSAS DELEGATION  
AMENDMENT—REPORT OF REFERENCE COMMITTEE

Recommend the following Substitute Recommendation 29-A on page 22, lines 19-22 of Report X of the Board of Trustees:  
19—Recommendation 29-A: That the AMA strongly recommends.

20—a system for contact tracing and partner notification.

21—for unsuspecting sexual or needle-sharing partners who

22—might have been HIV-infected should be established in

23—each community.

Recommend the following be added as Recommendation 29-E on page 22, line 43

Report X of the Board of Trustees:

43—Recommendation 29-E: That the AMA strongly recommends

44—the reportability of HIV sero-positive patients

45—to the departments of health of the 50 states for the

46—purposes of contact tracing and partner notification.

The profound show of support for my viewpoint suggested to me the silent majority was fed up with being intimidated and mesmerized by the vocal civil libertarian-homosexual advocate minority with its self-centeredness and calloused disregard for the health of others. It was past time to employ the same public health measures in the HIV epidemic as are used in other communicable and sexually transmissible diseases.

By this time all of the reference committees had concluded their hearings, and Speaker, Dr. John Clowe and Vice Speaker, Dr. Daniel Johnson were concerned that Reference Committee E might not finish its agenda until late in the night with over 43 more resolutions to be discussed. They suggested that the reference committee be divided into two sections, one to continue discussing AIDS issues and the other for the remainder of the agenda. Their suggestion got a resounding "No" vote. We then continued discussion of the last paragraphs of Report X.

The next resolution to be considered, Resolution 132, stated "Resolved, that the American Medical Association House of Delegates encourage state legislation to establish requirements for reporting and case follow-up for serious contagious diseases, to include AIDS nationwide."

I suggested to the reference committee that it should consider changing the word "AIDS" to the words "HIV infection." Although I would rather have this type recommendation in the overall policy statement, this change in Resolution 132 would have the same desired effect I sought.

I took the opportunity to point out to the reference committee, that although no votes are taken in reference committees, the sentiment in favor of the reportability of HIV sero-positive status, as expressed by the applause I had received, was greater in volume than the summation of all the applause other issues had received since we began deliberating that morning. This also received applause!

In the hallway, following the adjournment of the reference committee, I was approached by Dr. Roy Schwarz, Assistant Executive Vice President of the AMA, who complimented me on my endeavor and pointed out that for the first time there seemed to be sufficient support for this issue. He told me this subject had received heated debate in the committee which he

chaired that was responsible for composing Report X.

Monday evening I met with the Dermatology Section and reviewed for its members the deliberations on Report X. It was suggested by that group of eleven physicians that I seek to express my viewpoint on the floor of the House of Delegates. They further suggested the mechanism would be to ask one of our state's alternate delegates to let me have this position temporarily and that I should then ask one of our delegates to give me his seat when Report X was under consideration by the House of Delegates. At this meeting I was assured that each of them would solicit support of their individual state delegations in behalf of my positions.

I later talked with several experienced delegates and found out that the suggestion of my dermatologic colleagues to become a temporary delegate was seldom, if ever, done and would not likely be possible.

Late that night I received a phone call from Brian McNamee who told me he had a conversation with a member of Reference Committee E and that we would be pleased with their report. I felt elation, and also relief, that no further effort on my part would be needed.

The report of Reference Committee E was not available until late in the afternoon, Tuesday, December 5th. Unfortunately, the reassurance that Dr. McNamee had received was not forthcoming in the report. I felt frustration. Do we wait months or years longer for this done?

The reference committee report stated, "Based upon the testimony heard, the reference committee strongly recommends that in subsequent AIDS updates the Board specifically address the need for reportability of HIV sero-positive patients to public health agencies. . . ."

This presumably was put in to pacify us but it made me want to continue the challenge.

To further diffuse the issue, the reference committee did recommend that Resolution 132 delete the word "AIDS" and add the words "HIV infection" as I had suggested in the hearing.

I decided to contest this further, and during an afternoon recess I found the Speaker and Vice Speaker in the hallway. I was aware of the parliamentary point—Privilege of the Floor—so I asked them about how I could receive it. They, at first, were hesitant saying it usually is used for special addresses to the House of Delegates. When I explained my dilemma, they agreed that if I could get a delegate to ask the Speaker, at the appropriate time, I would be allowed two minutes to state my case.

At this point, I sought the help and advice of Dr. A.E. Andrews. Dr. Andrews agreed to ask the Speaker for my Privilege of the Floor on Wednesday morning when Report X was to be presented. Together we composed the following amendments. The first amendment would substitute a much stronger endorsement of contact tracing and partner notification for the weak statement included in the report. The second amendment would add a section to Report X recommending the reportability of HIV seropositivity rather than have such a recommendation contained in a separate resolution. We then presented our amendments, in behalf of the Arkansas delegation, to the AMA staff who printed them and placed them on the desks of the delegates Wednesday morning (see Table 1).

Tuesday evening I met with the McNameres and told them of my plans. They offered to lobby Wednesday morning for the Arkansas amendments in several delegations, including Ohio and New York.

After my planning session with the McNameres, Ruthe and I had dinner in the Golden Dragon Restaurant. As the meal ended, we were presented with the traditional fortune cookies. Although I am not one who wishes on stars, nor consults with a palmist or shaman, my fortune cookie message was very reassuring. It read, "The seeds of a wonderful project could be right under your nose." How prophetic!

After dinner, I prepared the statement I hoped to make to the House of Delegates Wednesday morning. Several revisions, later, I got the statement down to a two minute presentation.

By Wednesday morning, everyone at the meeting was ready to finish up the deliberations as quickly as possible. Debate was to be limited and I was concerned that I might not get the chance to speak. On the way to the House of Delegates meeting, I met Dr. Schwarz who asked me if I was happy with the report of the reference committee. I explained my displeasure. He told me he had seen the report in rough draft and suggested the original draft would have been more to my liking.

Before he was to present the report of Reference Committee E, I found the Chairman, Dr. Carl Evers, and told him I was disappointed with the report and I planned to speak for reportability of HIV sero-positive status. He looked surprised and said, "We gave you what you asked for in Resolution 132" and I said, "Yes, but it should have been incorporated as a part of Report X." At this moment a young gentleman stepped up to us and said, for both of us to hear, "It is a done deal, the trustees will not fight the Arkansas Amendments. Lonnie Bristow will speak in favor of adoption of the amendments." Oh what a feeling! I could smell success!

Finally, we arrived at the House of Delegates consideration of Report X. The Speaker chose to take each recommendation one by one. At the appropriate time, Dr. Andrews asked the Speaker to consider the two Arkansas Amendments and for me to be given the opportunity to speak in behalf of the Arkansas Delegation in support of the amendments. Privilege was given and I made my two-minute prepared speech.

I was pleased with the enthusiasm and the volume of applause that followed. Immediately, endorsement came from the delegations from Mississippi, New York, Virginia, West Virginia, Florida and the delegate from the American Academy of Dermatology. Opposition was basically from California and again, the USPHS spokesman was negative in his remarks.

A substitute motion was made to refer this issue back to the Board of Trustees. The vote to refer was by voice and the Speaker hearing the vote said he was in doubt of the response and asked for a second voice vote. There was then overwhelming vote to not refer.

At this point, I felt passage of the Amendments was assured. Belated endorsements were then given for the Board of Trustees by Dr. Bristow and for the reference committee by Dr. Evers.

Immediately, the Speaker called for a voice vote on the two amendments and there was no audible opposition. The amendments had passed!

I made my way to the side of Dr. Bristow and thanked him for the Board's support.

As the meeting ended, the Arkansas Delegation received much praise and thanks from our colleagues.

Probably, the most startling comment came from Brian McNamee when he pointed out that I came to the meeting as a non-delegate with an ax to grind, was given the



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rarely used Privilege of the Floor, and successfully changed AMA policy.

Later that evening, as the thrill of achievement began to subside, I began to think about the ultimate impact this change in AMA policy would have on laws and regulations throughout the country. Thousands of lives will be saved as this policy is put into action. I want everyone who has been involved in the Committee on AIDS activities since May 1987 to feel a part of and take pride in this accomplishment. Not just members of the committee who have inspired and nurtured each other, but the AMA staff, the medical students of P.A.T.E. and all the physicians and auxiliary volunteers. It is the summation of all their support and participation that brought about this success.

All of us who have taken on the responsibility of leadership from time to time have been critical about some aspect of the AMA and AMS. It behooves us to change what we perceive as wrong or poor policy because, like it or not, Congress and our state legislatures look to those bodies for advice and direction in matters that concern the public health and how medicine is, and will be, practiced.

There is a system and it works but we must be willing to do the homework and sacrifice the time and energy to work the system.

—  
"Mr. Speaker, Members of the House of Delegates:

I am William Jones, Chairman of the Arkansas Medical Society's Committee on AIDS, member of the Governor's Advisory Committee on AIDS, and President-Elect of the Arkansas Medical Society.

On Monday, the debate in Reference Committee E over each aspect of Report X was to be expected. Basically, Report X of the Board of Trustees is a significant improvement of Report YY-87.

In June, I pleaded with Reference Committee E to ask the House of Delegates to endorse contact tracing and partner notification. Subsequently, all of the resolutions on AIDS were referred to the Board of Trustees to update the HIV policy of the AMA. Most of those resolutions supported contact tracing, partner notification and the reporting of HIV sero-positive persons.

Report X endorses contact tracing and partner notification. However, there is one glaring deficiency in the report. Namely, it fails to recognize the need for reporting HIV sero-positive persons to the health departments of the various states. AIDS is reportable in all 50 states. HIV sero-positive status is reported in many states and others are considering such legislation at this time. It must be remembered that HIV infection is a continuum of disease leading to death. The infected person is infectious to others from very early in his or her infection.

For too long we have failed to apply the same public health measures to contain the HIV epidemic as are taken to control the spread of other communicable and sexually transmissible diseases. This has resulted in over 65,000 reported deaths in this country. How many more lives have to be lost before we take a stand that, every physician in this country knows, should have been taken several years ago? It is past time for the American Medical Association to take a firm position and emphatically state the importance of reporting HIV sero-positive patients, contact tracing and partner notification. Concerns about the occasional breach of privacy and confidentiality of one individual have to be second consideration to the right of the public to be protected from this fatal viral epidemic.

The longer we delay taking this position, the wider spread the epidemic and the greater the tragedy in loss of lives that could be saved by these measures.

I urge you to vote affirmatively on the two amendments to Report X."—Dr. William Jones.

HOUSE OF REPRESENTATIVES,  
Washington, DC, March 5, 1990.

JAMES O. MASON, M.D.,  
Hubert H. Humphrey Building, Washington, DC.

DEAR MR. MASON: I have enclosed for your review a remarkable firsthand account of the December 3-6, 1989 Interim Meeting of the American Medical Association in Honolulu, Hawaii. This account, written by William N. Jones, M.D., the President-Elect of the Arkansas Medical Society, raises some disturbing questions with respect to the representation of formal U.S. Public Health Service (USPHS) policies at this important meeting. Other physicians who participated in the Honolulu deliberations have confirmed Dr. Jones' account.

As you may know, the overwhelming majority of AMA delegates adopted two resolutions pertaining to the HIV epidemic which reflect my own preferred approach to containing the spread of infection. The Delegates adopted the following two resolutions:

Recommendation 29-A: That the AMA strongly recommends a system for contact tracing and partner notification for unsuspecting sexual or needle-sharing partners who might have been HIV-infected should be established in each community.  
Recommendation 29-E: That the AMA strongly recommends the reportability of HIV sero-positive patients to the departments of health of the 50 states for the purpose of contact tracing and partner notification.

As you can see from Dr. Jones' account, it appears that the Delegate from the USPHS repeatedly opposed these resolutions at the interim meeting and, in fact, was one of only a few physicians to do so. To the best of my knowledge, the formal USPHS position with respect to HIV reporting was set forth in the July 21, 1989 issue of the *Morbidity and Mortality Weekly Report* (MMWR). That report urged states to adopt reporting measures, arguing:

"HIV infection reports are useful in directing HIV-related prevention activities such as patient counseling, partner notification and referral for appropriate medical management (e.g., evaluation for prophylaxis against *Pneumocystis carinii* pneumonia). Reporting of HIV-infected persons may enable earlier recognition of persons with or at risk of HIV infection and earlier intervention to prevent further spread of HIV. Recent guidelines for initiation of therapy in some HIV-infected persons emphasize the need for identifying persons who need treatment before the diagnosis of AIDS is made. HIV infection reports are also useful for guiding pediatric medical and social support programs, including programs for infants whose infection status may remain undetermined until they are (under) 15 months of age."

The formal position of the USPHS with respect to partner notification programs was set forth in the MMWR of March 14, 1988, in which the USPHS recommended that the prospective and previous sexual and needle-sharing partners of infected persons be informed as to their potential exposure to HIV infection and urged to undergo HIV testing and counseling.

For the USPHS Delegate to oppose the AMA resolutions in Honolulu appears to be an unconscionable dereliction of his duty to faithfully represent the positions of the

USPHS. I would appreciate it if you or your staff could respond to the following questions:

Do you believe that Dr. Jones' description of the USPHS Delegate's activity is accurate?

If you believe it accurately describes the events in Honolulu, were you aware of this activity and have you taken any steps to reprimand the individual involved? According to the AMA's 1988-89 directory of the House of Delegates, the alternate Delegate from the USPHS is James D. Felsen, M.D. Did Dr. Felsen represent the USPHS in Honolulu?

Have you taken any measures to guarantee that such unilateral actions are not repeated in the future?

Finally, does the USPHS contemplate making an attempt to inform the AMA leadership and the hundreds of AMA Delegates of the true USPHS positions on these important public health issues?

Thank you in advance for your time and assistance.

Sincerely,

WILLIAM E. DANHEMEYER,  
Member of Congress.

Mr. Speaker, let me say that the significance of this action of the American Medical Association in Honolulu last December cannot be overstated. This epidemic has marched across this land, and today we have a civil rights response being pursued in 11 States of the Union containing 78 percent of the cases. My State of California is in the unenviable position of being the State with the second largest number of cases, 20 percent, with the State of New York having about 23 percent. In both these States, in New York and California, a civil rights response is currently being pursued.

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Mr. Speaker, it is a tragedy that such is the case. Dr. Axelrod, the health officer of New York State, should have been relieved from that job at least 3 years ago by the Governor of that State who should be watching out for the civil rights of the infected at least on the same basis as the civil rights of the infected.

Similarly, in my State of California, Dr. Kaiser, the health officer, should have been relieved from his job at least 3 years ago by the Governor of the State, Governor Deukmejian. I am happy to say that the State Republican Party in California in convention the weekend before last adopted a resolution requesting the California Medical Association to adopt a policy dealing with HIV infected people consistent with AMA policy. That State Republican Party and convention also adopted a resolution requesting the Governor of the State of California, Governor Deukmejian, to exercise his discretion which he has under the existing law to add HIV positive people to the list of reportable diseases.

Mr. Speaker, the time has long passed that this Nation would continue to treat the AIDS epidemic and HIV carriers as a civil rights issue. It should be treated as a public health issue, and what the AMA has done is

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now placed its voice as the official voice of organized medicine behind steps that are needed across this land to deal with the epidemic as a public health issue.

Tomorrow before a committee of this House, one of the housing subcommittees, efforts will be made to expand housing programs in this country to establish a hospice for treating persons with AIDS. I personally believe that treating the people with this tragic disease, for which we do not now have a cure, but hopefully will find one in a hospice setting, is a good alternative rather than a hospital setting.

We also will be considering later in this legislative year appropriation bills to deal with, hopefully, finding a cure to the epidemic.

The reality is that we Federal taxpayers are spending about \$1.2 billion this year to control the AIDS epidemic. About \$800 million is being spent to find a cure or a vaccine for the virus. About \$400 million is being spent in the area of education, which has a certain ring of credibility to it in terms of preventing the transmissibility, but the reality is that the education-only approach that has been pursued essentially by the U.S. Government, as well as by the States with the largest number of cases, namely New York, California, Florida, and Texas, has failed to stop this epidemic.

This epidemic, tragically, is the first politically protected disease in the history of the country. Those that are HIV carriers should be reportable to the health care system in confidence so that we can do contact tracing. That is why we pay taxes in this country, to provide for the functioning of the health care system.

When the House last considered this issue, in September 1988, this Member from California offered an amendment to the bill then being considered by the House which dealt with the very issue the AMA considered at its convention last December in Honolulu. My amendment would have required that as a condition of the receipt of Federal money by any State in the Union to deal with the epidemic, that the State would have to have in place a law requiring that HIV carriers be reported to public health authorities and that we conduct contact tracing. The amendment at that time was not adopted by the House. I believe there were approximately 75 votes for it. In speaking in opposition to that amendment my opponent, one of them on the floor, was able to observe that he was then voicing the support of the American Medical Association in opposition to my amendment dealing with reportability for HIV carriers.

Mr. Speaker, I mention this to the House because it illustrates just how important it is what the AMA did in Honolulu last December, because now, when this issue comes to the floor again, this Member from California will be able to say that I spoke for the

voice of organized medicine in America, that HIV carriers, whatever their status in life, whether they are intravenous drug users, whether they are heterosexuals or homosexuals, whether they got the virus as a result of a blood transfusion, whether they are hemophiliacs or whatever, those people who are carriers of that fatal virus, when their status is determined by their physician, would be reported to public health in confidence and that we would then conduct contact tracing. This is the means whereby our society has dealt historically with efforts to control the transmissibility of venereal disease, curable or noncurable, in America.

Mr. WAXMAN. Thank you, Mr. Dannemeyer.

Our first witness today is Annette Strauss, the mayor of Dallas. Dallas is one of the Nation's hardest hit cities with more than 2,300 cases of AIDS and a growing number of people with no source of payment for health care. I would like to welcome you, Mayor Strauss, to this meeting and I know you are on a very tight schedule because I think at noon today, you are receiving an award in midtown Manhattan. It is the national Mother's Day Committee and you will be singled out as the outstanding Mother of the Year. Congratulations to you on this award. We are pleased that you are taking the time to be with us and we would like to hear from you.

#### STATEMENT OF ANNETTE STRAUSS, MAYOR, DALLAS, TX

Ms. STRAUSS. Thank you, thank you very much, Chairman Waxman, and thank you for recognizing my time constraints and allowing me to go first, and thank you, Mr. Dannemeyer.

Dallas County's first AIDS case was diagnosed in 1981 when there was no hope of effective treatment, let alone a cure. Now, patients have more hope because new treatments are available. Without such treatment, patients used to die within 1 year of diagnosis. Now the rate of death within the first year has been reduced to 40 percent nationwide.

Parkland Memorial Hospital, in Dallas, has reduced it to less than 30 percent.

Medical science clearly has lengthened the lives of AIDS patients, and as a result, the disease incapacitates them over longer periods, making them more dependent on social services.

Approximately 60 percent of Dallas County's 2,300 persons with AIDS are treated at Parkland Memorial Hospital's AIDS Outpatient Clinic and the majority are indigent. On any single day, 20 to 30 AIDS patients are hospitalized there for acute infections. Parkland is the county's only public hospital, and like most public hospitals, the burden of caring for AIDS patients rests with it.

The hospital is at capacity and the everincreasing case load is a difficult budgetary strain. The AIDS epidemic started in Dallas primarily among the Anglo homosexual male population, but the disease is now steadily increasing among the nonwhite, the nonmale and the nonrich.

Compared to the overall volume of infected individuals, the number of infected women is relatively small, but it is growing rapidly. Approximately 150 women and children have been diagnosed in Dallas as being infected and 1 out of 8 patients in Parkland's AIDS Clinic is a woman.

Of the 23 women currently being treated at Parkland for full AIDS, 11 were diagnosed within the past year. They come from all socioeconomic groups and lifestyles. The majority say they did not engage in any of the high-risk behaviors associated with AIDS. They obviously were unaware that their sexual partner had and they did not recognize high-risk behavior.

Some are well to do and educated. They go to a public hospital for treatment because they are afraid to use their insurance for fear their employers or friends will find out.



Most of these women are in their childbearing years. Some have children who are infected at birth. In recognition of their unique needs, Parkland has established a special clinic where mother and child can be seen together.

A community agency has also recognized the special needs of such patients and has established a home called Bryan's House to help infected women and children. It opened less than 2 years ago and is licensed to care for nine kids. The house is overflowing and the agency is now expanding its facilities if the money can be raised so Bryan's House can provide day and residential care for 40 children. The need is there.

When you see these youngsters, the reality of the spread of the disease stays with you. They look like any other child, innocent and vulnerable.

The case management system that has worked so well in helping the very different AIDS population that preceded them is already helping infected women and children. Case management was established midway in the epidemic to develop a continuum of care through wide participation by many health care and community-based agencies.

As many as 40 community service agencies help through an umbrella agency, called AIDS/ARMS Network. As the patient's illness progresses, and they become more dependent, case management assures that they receive help for their problems, whether emotional, financial or medical.

Hospices, respite and day care, food services and buddy systems are all part of the case management network in Dallas. The church-based AIDS Interfaith Network is now supplementing the very successful buddy system. It is good to see this coordination between church and gay support groups who led the fight so long, but whose ranks are being disseminated by AIDS.

All of these groups are part of a continuum of care that provides services that health care providers like Parkland cannot. They have helped in AIDS education efforts, spreading the word on how to prevent it, and the importance of seeking treatment early.

This has helped curb the spread of AIDS among the gay community, but similar efforts may be more difficult among Dallas' newest patients at risk. Health care professionals say the reason for this is that the city's homosexual community is more cohesive, eager to form support groups, and has always been heavily involved in the education effort.

As I mentioned earlier, many of the women being treated at Parkland had no notion that they were exposed to AIDS. They didn't do drugs. They weren't prostitutes. There certainly isn't any cohesiveness among them. The poor also are less likely to form support groups or champion a prevention effort, while cultural barriers may block AIDS education among minorities.

Right now, we don't know how we will break the information barriers to these diverse groups, but we must try. Lack of funding is also a problem for which solutions are very scarce. We certainly concur with H.R. 4080, which provides assistance for low-income people with AIDS or HIV infection and with H.R. 4470, which targets relief for cities with more than 2,000 AIDS patients.



Unfortunately, Dallas has become more qualified every single day. Relief funds should be directed toward hospitals like Parkland that provide a disproportionate share of health care and also to those agencies that work in partnership to provide a continuum of care in our community.

Federal assistance payments for early intervention health care services are desperately needed. Although research efforts have developed therapies that can forestall the progression of AIDS and its accompanying infections, because poor people cannot qualify for Federal Medicaid assistance until they develop the full disease, preventive therapies are too late for them.

The result is that these patients get sicker and the Federal system then begins to pay for only the most expensive care, inpatient hospitalization. This must be changed. Help from Medicaid is currently little or no help because less than 12 percent of the AIDS patients in Texas even qualify for it.

The impact on Parkland Hospital is enormous. Because Parkland is a public hospital, local taxpayers must pay the bill that Medicaid won't. Ad valorem taxes pay for the drug therapies that keep AIDS patients alive and out of the hospital. It is an endless drain on local tax dollars, and as you all know, every community has a finite tax base from which these services can be funded.

The interesting thing about the epidemic is that as health care providers prolong the lives of their fatally ill patients, success increases costs. The case load is swelling with new and old patients. At the moment, Parkland treats in the neighborhood of 1,300 patients each month in its outpatients clinic. The cost of this burden is one any humane person would be pleased to pay, but in Dallas, it is happening in the face of a recession at an already overcapacity public hospital overwhelmed with the needs of its other patient population, the poor, the homeless, the elderly, the working poor and the uninsured.

Unfortunately, the needs of all these patients are in competition for scarce resources. As the mayor of the city of Dallas, I urge you to provide the support to address the compelling needs of persons with AIDS in our community.

Thank you very much.

Mr. WAXMAN. Mayor Strauss, I want to thank you for an excellent statement. I know that you are doing as best you can under difficult circumstances in Dallas, given the low participation of Medicaid in dealing with the problems and the inadequacies in our whole health care system. I want to thank you for your presentation to us.

We may have some specific questions and we would like you to respond in writing for the record, but I know that you must be leaving to catch a flight and I thank you so much for being with us.

Ms. STRAUSS. Thank you, sir, and thank you, all of you, for what you are doing to fight AIDS. We appreciate it.

Mr. WAXMAN. Our second panel today, I would like to welcome two of our colleagues, one of whom I see with us so far, the Honorable Frank Lautenberg, and we are going to be joined by the Honorable Frank Guarini. Both represent New Jersey, one of the States that is hardest hit by the AIDS epidemic.

Senator Lautenberg, we are delighted that you have taken time to come to address us and to point out some of the concerns that you and your constituents have and recommendations and changes and improvements or further progress in this legislative issue.

**STATEMENT OF HON. FRANK LAUTENBERG, A U.S. SENATOR  
FROM THE STATE OF NEW JERSEY**

Senator LAUTENBERG. Mr. Chairman, I thank you very much, and note with surprise and admiration that this subcommittee apparently starts on time. Other than the traffic and the cherry blossoms that remain, I would have been here a little bit earlier and I thank you very much for the opportunity to appear before you. I commend you for holding this hearing, Mr. Chairman, for taking on serious issues and applying your considerable energy and skill to it. I applaud your leadership in combatting the tragedy of AIDS.

By boosting research, by getting new treatments into the hands of the sick and by protecting the rights and the dignity of those suffering from AIDS, you have been an inspiration to countless victims and families that have had to confront the painful reality of this terrible disease.

I would like to focus this morning on H.R. 4470, the AIDS Prevention Act of 1990. I am an original cosponsor of a similar bill just approved by the Senate Labor and Human Resources Committee. It is S. 2240. We desperately need AIDS disaster relief and we need it now.

The AIDS epidemic in the country has reached crisis proportions. To date, more than 121,000 cases have been reported to the CDC, and unfortunately, more than 8000 of these cases have been reported from my own State of New Jersey, one of the five States nationwide that accounts for 64 percent of all AIDS cases.

In our cities and counties throughout the Nation, hospitals, clinics and health care providers are struggling to provide services to AIDS victims, but in many areas hardest hit by the AIDS epidemic, particularly our urban areas, it has been an uphill battle. Public health systems are being pushed to the absolute limits as they struggle to fight the AIDS epidemic. Our urban hospitals, already overcrowded, short of staff, are bursting at the seams trying to serve increasing numbers of AIDS patients. It is hard to find beds. It's hard to find the money to care for AIDS victims who lack insurance or a job or even a home.

Our hospitals and cities and counties desperately need the help offered by the AIDS Prevention Act of 1990.

I have a concern that I would like to raise with the chairman and the members of this subcommittee about title III of the bill. It is the section of the legislation that would provide grants for emergency assistance to areas with substantial need for services for AIDS.

To qualify for assistance under title III, a metropolitan area must have reported more than 2,000 cases of AIDS to the Centers for Disease Control. Under the bill, 13 areas, including Newark, NJ, would automatically qualify for emergency grants to provide relief for their public health systems because they have more than 2,000 cases. This type of assistance is critical, but I am concerned

that the bill misses one of the hardest-hit areas in the country, and it misses that area because it just looks at one factor, and that is the number of cases.

Twenty-six hundred cases in an area of 5 million, like Philadelphia, isn't the same as 2,000 cases or even 1,500 cases in an area of 500,000, like Jersey City—Hudson County, NJ. Jersey City is reeling under a much bigger burden and I believe it is our job to help that smaller city.

In Philadelphia—and I just use that as a comparison because the numbers seem to fit well—those 2,600 cases are spread over eight counties with almost 5 million people. In Chicago, there are 3,100 cases among over 6 million people. Now, the burden for caring for these cases is shared by a much broader base of government and taxpayers.

It is a much different story in Jersey City. It is one of the hardest-hit areas in the country. It has had to cope with over 1,400 AIDS cases and it is an area with just over 500,000 people. So it doesn't have the 2,000 requirement, but it certainly has a percentage of the population that is significantly higher than many other places. It means that 0.26 percent of the population suffers from AIDS. That is five times the incidence rate of Philadelphia or Chicago.

In fact, its incidence rate is higher than all but two of the areas that qualify for title III assistance under the bill. Certainly Philadelphia and Chicago need help, but so does Jersey City.

I have a letter for the record, Mr. Chairman, that I would like to submit, which explains this concern in more detail. It is signed by myself, Senator Bradley, Congressman Guarini and Congressman Torricelli.

We propose a modification to the bill that would make the incidence rate a factor in determining title III eligibility and I hope that the chairman and the members of this subcommittee will seriously consider it before it marks up the bill.

I thank you very much for this opportunity to testify.

[The letter referred to by Senator Lautenberg follows:]



FRANK R. LAUTENBERG  
NEW JERSEY

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TRANSPORTATION CHAIRMAN  
COMMERCE JUSTICE STATE AND JUDICIARY  
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# United States Senate

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AND PUBLIC UTILITIES

COMMITTEE  
TRANSPORTATION

April 19, 1990

The Honorable  
Henry A. Waxman  
Chairman  
Subcommittee on Health and the Environment  
House Committee on Energy and Commerce  
House of Representatives  
Washington, D.C. 20515

Dear Chairman Waxman:

When the Subcommittee on Health and the Environment marks up H.R. 4470, the AIDS Prevention Act of 1990, we urge you to include a provision that would enable the PMSA of Jersey City in Hudson County, New Jersey to qualify for Title III assistance.

Under the bill as drafted, the area does not qualify for Title III funding because it does not meet the 2,000 AIDS case threshold. However, Jersey City is clearly one of the most heavily impacted metropolitan areas in the country and is deserving of Title I aid. The PMSA of Jersey City currently has 1,428 AIDS cases. Its estimated population is about 550,000. This means that .26% of the population in Jersey City suffers from AIDS.

Jersey City's .26% incidence rate is higher than all but two of the areas that do qualify for Title III assistance under the bill. It is five times the incidence rate in Chicago and Philadelphia, three times the incidence rate in Dallas, and two and a half times the incidence rate in Washington, D.C. Because of the extremely high numbers of AIDS victims in the area compared to the population, it is undeniable that the area is heavily impacted and in need of the kind of emergency assistance that would be available under Title III of the bill.

Unlike many of the areas that will receive Title III assistance under the legislation, only one county is in the PMSA that includes Jersey City. For that reason, only the AIDS cases in that one county are counted toward the 2,000 threshold. At the same time, because of the Census Bureau's definition of PMSAs, other areas that qualify for Title III assistance can count AIDS cases from several counties -- including a total population several times the size of Jersey City -- to reach the 2,000 threshold. For example, the PMSA in which the city of

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The Honorable Henry A. Waxman  
 April 19, 1990  
 Page 2

Philadelphia is included includes eight counties, three of which are in my state of New Jersey.

We do not believe that Jersey City should be prevented from qualifying under Title III of the bill because the Census Bureau has included only one county in that particular PMSA. If for example, the PMSA in which Jersey City is located included two other counties, neighboring Bergen and Passaic Counties, nearly 2,500 AIDS cases would be attributed to the area, more than the 2,000 needed to qualify for Title III funding. The total population for the three counties -- roughly 1.3 million -- would still be less than the population of other PMSAs that are eligible for Title III assistance.

We propose that the Committee include the attached language in the bill to provide assistance to any metropolitan area with a population of 500,000 or more with an incidence rate of AIDS that exceeds .2% of the population. This would enable the heavily impacted PMSA of Jersey City to qualify for assistance under Title I of the bill. No other areas would be added under Title III because San Francisco, San Juan, New York, Newark, and Miami -- the only other areas that could also meet that standard -- already qualify under the 2,000 threshold. Making this modification to include Jersey City would certainly be consistent with the goal of providing assistance to the areas in greatest need.

The need for assistance in heavily impacted metropolitan areas like Jersey City is tremendous. Our cities and counties are struggling to provide sorely needed services to AIDS victims and their families. We applaud your initiative in developing this legislation. We hope you will agree that Jersey City is among those cities that are in greatest need and that we can work together to include the area under Title III of the legislation.


We appreciate your consideration.

Sincerely,

  
 Bill Bradley

  
 Frank R. Lautenberg

  
 Frank J. Guarini

  
 Robert G. Torricelli

Proposed Amendment to H.R. 4470

On page 29, line 19, after the words "Disease Control", insert "or is a metropolitan area with a population of 500,000 or more with an incidence rate of AIDS that exceeds .2% of the population."

Mr. WAXMAN. Thank you, Senator. You raised an excellent point that I think we need to give full consideration to as we look at trying to be of assistance to the areas that are hardest hit. Certainly Jersey City is reeling under its burden, as some of these other areas that have been singled out.

Unfortunately, this whole country is going to be faced with a tidal wave of cases and the health care cost for those cases if we don't deal as quickly as possible in a manner to get the early intervention drugs to people to prevent all the opportunistic infections and full-blown AIDS and pneumonia and even after we do that, we will still have so many cases yet to go into our health care system without adequate coverage for those people.

You highlighted a point for us that we definitely want to take into consideration and I thank you for it.

I know you must run. Let me just see if any of our colleagues have a question. If not, we are going to have to let you go on to your other business.

Any quick questions of the Senator, Mr. Dannemeyer?

Mr. DANNEMEYER. Yes. I want to welcome the Senator. I suspect you may not be aware of it, and I don't mean to put you on the spot, but the official voice of organized medicine in your State, the New Jersey State Medical Society, has endorsed the bill that I introduced last year, H.R. 3102, the Public Health Response Act of 1989. I don't know if you are aware of that or not?

Senator LAUTENBERG. I am not aware, Congressman.

Mr. DANNEMEYER. So I am just—if you know about it, H.R. 3102, I would appreciate your comments about it.

Senator LAUTENBERG. I will get back to you. I am not fully familiar with it. New Jersey has this unenviable position of having a large number of AIDS cases. We are the most densely populated State in the Union. We are also one of the most inventive States. We are third among patent producers and ninth in size. We are an energetic, vibrant State and, unfortunately, we haven't had until not too long ago, the kind of medical facilities that befit a State of our size and our technological skill.

We are just knuckling under in number of cases of AIDS—

Mr. DANNEMEYER. You have the fourth highest total of any State in the Union. That is not anything to be proud of, but it is a fact.

Senator LAUTENBERG. Absolutely.

Mr. DANNEMEYER. My State of California, by the way, has the second highest total.

Senator LAUTENBERG. If we had your population, it would be a little crowded in New Jersey's boundaries. But you also have an energetic and talented population in your State and if I am not mistaken, I heard some very exciting news last night about a discovery that I think came out of California that would help cure a blood disorder, cancer of the blood cells, leukemia among them, with one treatment. I don't know whether you saw it. It was stunning. One treatment, no side effects, and people walked away after that.

Mr. DANNEMEYER. I would ask you to take a look at H.R. 3102. I would welcome your endorsement of it, as I would the other members of the delegation from the great State of New Jersey, because the cornerstone of H.R. 3102, very candidly, is a process that regrettably, as I said in my opening statement, many States in the

Union have not put in place, namely, reportability for HIV carriers and contact tracing.

I don't know whether you have dug into the practice of medicine deeply enough to appreciate the significance of that step that has been overlooked by too many public health officials in this country in dealing with the epidemic. But if you haven't dug into it enough to——

Senator LAUTENBERG. We will take a look.

Mr. DANNEMEYER. I would recommend that to you, sir, because when you do that digging, as I did in developing my approach to this issue, I came to the realization, why in the world do those of us outside medicine—I am a lawyer by profession—I don't know what your background is, but you——

Senator LAUTENBERG. I am not a lawyer.

Mr. DANNEMEYER [continuing]. Are not a doctor, are you?

Senator LAUTENBERG. I am not a lawyer, no.

Mr. DANNEMEYER. Are you a doctor?

Senator LAUTENBERG. I am a businessman.

Mr. DANNEMEYER. All right. The problem we lay men and women have in the country is that we necessarily rely on the leaders in the medical profession and in the public health world to give us guidance as to how we are going to establish public policy. One of the tragic aspects of the whole epidemic is that the American public has been tragically failed by certain leaders of the medical profession across this country who have permitted themselves to be placed in the position of treating it as a civil rights issue, not a public health issue.

Senator LAUTENBERG. We will certainly take a look.

Mr. WAXMAN. Mr. Rowland.

Mr. ROWLAND. Sir, thank you very much for being here and congratulations on not being a lawyer.

Senator LAUTENBERG. I think New Jersey is one of the few States in which neither Senator is a lawyer, but both of us are members of the Hall of Fame. Everyone knows that Bill Bradley is a member of the Hall of Fame. It is basketball. I am a member of the Hall of Fame of information processing. It doesn't really take a lot of people's fancy when I say that.

Mr. ROWLAND. You certainly do point out what I believe is an area that needs to be addressed in this legislation, and that is those areas where there is less than the population that is required for these impact funds.

The National Commission on AIDS has just completed this week, Monday and Tuesday, site visits in my home State of Georgia in the rural areas to look at what is taking place there. There is the largest percent increase in the number of AIDS cases in the rural areas, versus the urban areas. Thirty-seven percent in rural areas over the past year, as compared to 5 percent in the urban areas—that is, increase, not the number of cases.

So it is very important, I believe, as you point out, that we address those areas where there is a significant increase in numbers of cases outside of these large urban areas. That is something that we will be looking at and something that we have already talked about here addressing, so I appreciate you focusing attention on that very problem.



Senator LAUTENBERG. Thank you very much.

Mr. WAXMAN. Senator, thank you very much, and while you are looking at these bills, take a look at Senator Moynihan's bill, which is a companion to our measure, on Medicaid to cover early-intervention drugs.

Senator LAUTENBERG. I always look at Moynihan's bills. He is senior to me on the Environment Committee. Thank you.

Mr. WAXMAN. Thank you very much for being with us.

Without objection, we have a statement by Congressman Frank Guarini. I don't know if he is planning to be here or not, but I think he is on the Budget Committee, and today the Budget Committee is very busy. Without objection, his statement will be made part of the record. [See p. 301.]

Our third panel is made up of people who have worked and lived with AIDS for years now, people who have taken up the efforts that the government has let fall.

David Wexler is the chair of the board of directors of AIDS Project Los Angeles, the oldest and largest of the southern California voluntary AIDS groups. APLA serves my home district and my constituents and has been the lifeline for many who have no place else to turn. The organization, its employees, and its volunteers are very literally life savers.

Merv Silverman is the president of the American Foundation for AIDS Research. His organization is the largest private AIDS foundation and he has been a recognized authority on public health in AIDS since the earliest days of the epidemic.

Louis Grant is a person who is living with AIDS. He was diagnosed with AIDS a number of years ago and has lived with the daily reality of health care systems and their difficulties and successes.

Gabe Kelen is the director of research at the Department of Emergency Medicine of the Johns Hopkins School of Medicine. He deals with the frontline of providing health care to people with AIDS in an emergency room setting, many of them having no previous or subsequent primary medical services.

Mark Smith is the associate director of AIDS Services at Johns Hopkins. He has lead the way in the development of outpatient early intervention services and primary care that we all hope can, if adequately financed, reconfigure the way AIDS care is delivered in the future.

Gentlemen, we are pleased to welcome you to our subcommittee hearing this morning. Your prepared statements will be in the record in full. We would like to ask each of you, if you would, to please limit your oral presentation to us to no more than 5 minutes.

We would like to start with Mr. Grant, if we might.



STATEMENTS OF LOUIS GRANT, NEW YORK, NY; DAVID WEXLER, CHAIR, BOARD OF DIRECTORS, AIDS PROJECT LOS ANGELES; GABOR D. KELEN, DIRECTOR OF RESEARCH, DEPARTMENT OF EMERGENCY MEDICINE, JOHNS HOPKINS SCHOOL OF MEDICINE; MARK D. SMITH, ASSOCIATE DIRECTOR OF AIDS SERVICES, JOHNS HOPKINS SCHOOL OF MEDICINE; AND MERVYN F. SILVERMAN, PRESIDENT, AMERICAN FOUNDATION FOR AIDS RESEARCH

Mr. GRANT. Good morning. As you said, I am Louis Grant, from New York. I am a person with AIDS, a so-called long-term survivor in that I have lived with it for 8 years. I am also a member of the boards of the Gay Men's Health Crisis in New York City and the Community Research Initiative.

I am here today to say that it is possible to survive AIDS, to live with it through early diagnosis and treatment and that now there are drugs available that make that possible and have it made it possible for me. As you see, I am a thriving survivor, but I am among the lucky.

I grew up taking good primary care for granted. My parents, though working class, hard working class people, made that possible for me and in my later adult life, I continued to maintain contact with my doctors on a regular basis so that, as an active, sexually active adult, as the AIDS crisis—although we didn't call it that at that time—began to increase and I was losing friends, I was seeing my doctor quite regularly in order to make sure of my status. Finally, at a point 8 years ago, I was diagnosed with AIDS, that is Kaposi's sarcoma, cancer.

At the time, there were no accepted treatments for AIDS, though, as a well-educated man, I was able to reach out on my own to study literature, to read various newspapers, and I found an experimental drug trial in Brooklyn on maltrexone, which I joined and I continue to take maltrexone and it seems to have stabilized my condition.

But I say, I am among the exception in that my own background of primary care and my knowledge and willingness to go out on my own and find treatments have enabled me to live these years. I pieced together a survival package for myself, which included this drug and others, more recently pentamidine and AZT, as well as nutritional supplements and an accelerated schedule of medical checkups.

I am also the Associate Director of the Center for Constitutional Rights in New York, so I have continued these last 8 years to be a taxpayer and an active participant in my community, which I think we all desire, that citizens in this country be able to do.

This crisis has meant that we have lost a number of very talented people, that our tax rolls are depleted, not only by the fact that they are not able to pay taxes, but the drain for medical care has been astronomical. I advocate for this kind of early intervention which allows people like myself to continue to do what we must do to earn a living and pay our taxes and participate in our community lives.

As I have said before, I am an exception to the normal scenario of quick move from diagnosis to death. Early detection, followed by

treatment, can mean survival, thriving survival for many of us. In New York City, the case load is expected to increase from 22,000 AIDS cases reported at the end of 1989 to 33,000 by the end of this year. According to the New York City Commission on AIDS, up to 225,000 New Yorkers are HIV-positive. Of these, the New York City Department of Health reports that 117,000 have a T-cell count below 500. By the recommendations of the Secretary of Health, those 117,000 should be receiving medical care in an early intervention program. According to this recommendation, the number of people needing services will increase by tenfold.

Unfortunately, though we know that this is important, in fact, at the moment, the early intervention is not taking place. GMAC, among the various community-based groups, private groups, suggests that people be tested for HIV, but then where do we send them if they do find that they are positive? That is a major question.

At the moment, we are treating 2,000 clients and anticipate a 100 percent increase to 4,000 within a year. We are primarily privately funded, but those funds are limited, though they are substantial.

The various examples of the crisis are rampant. In this Sunday's New York City Newsday, an article was printed about the problem of finding medical professionals in the area of AIDS. The various programs that directed doctors, young doctors, medical students into service in innercity areas have decreased or are nonexistent and medical people are not choosing to go into this area.

I could make many other examples. Basically, I am here to advocate for this bill and to indicate that this person, myself—I have been able to survive and I hope that many others, as I have watched over the years, will be able to survive with AIDS through early intervention and detection.

Mr. WAXMAN. Thank you very much for your testimony and your willingness to come here, Mr. Grant.

Mr. GRANT. Thank you.

Mr. WAXMAN. We would like to hear from Mr. Wexler next.

#### STATEMENT OF DAVID WEXLER

Mr. WEXLER. Thank you, Mr. Chairman. I should admit at the start, from what I have heard this morning, in the interest of full disclosure, that I am a lawyer.

Mr. WAXMAN. I won't hold it against you.

Mr. WEXLER. I am also the chair of the board of AIDS Project Los Angeles, which is the largest AIDS service organization in Los Angeles County.

We serve 2,250 persons with AIDS, which is 68 percent of the people in Los Angeles County with AIDS. I am a volunteer. AIDS Project Los Angeles operates with 1,100 volunteers. We have an annual budget of \$10.5 million, 70 percent of which is raised from the private sector.

We provide counseling, housing, food, transportation, buddy program and other services, educational programs. Our hotline answers 5,000 calls a month.



There are 250 other organizations in Los Angeles County which provide services to people with AIDS. They range from education, testing, preventive therapy, medical and social services. I am here to urge you to provide funding for early intervention of medical care to HIV-infected persons, to delay—and prevent the onslaught of AIDS and to assist community-based organizations providing services to persons with AIDS. The AIDS population is increasing at an alarming rate.

AIDS Project Los Angeles and other community-based organizations are being swamped with clients. The projected numbers for the near future are staggering. We are told that by the end of 1993, our client population will quadruple.

Now, the Los Angeles County strategic plan, which is about to be issued, estimates that by the end of 1992, 13,000 HIV-infected people in Los Angeles County will require medical treatment and 99,000 asymptomatic people will require monitoring to determine when that medical treatment is necessary.

In the early years of AIDS, there was little you could do, but science has now developed drugs which will delay the onslaught of AIDS in most infected persons for years. By proper testing to identify HIV-infected persons, monitoring such persons and early medical intervention when indicated, we can increase the length of survivability, the years of healthy and productive life of people with AIDS by years.

By establishing a continuum of care, we can keep HIV people well, working, contributing to society, paying taxes. We can delay the time of their medical and physical needs and the depletion of the funds that are available, both to government and to community-based organizations.

More importantly, we can increase years of productive satisfying life for hundreds of thousands of people. We believe that because of the long incubation period between the infection and development of AIDS, tens of thousands of persons in Los Angeles County and hundreds of thousands of persons in the United States will develop seriously impaired immune systems in the next 2 years. Unless treated, these people will develop AIDS. We must find these people; we must monitor them and we must provide the drugs which are now available to keep them healthy and productive. We will thereby save far greater costs to society, both in the loss of contributing persons and the costs of treating persons with AIDS, which will result when these ignored human beings develop AIDS.

I implore this Congress to provide the funds necessary to allow testing, monitoring and medical treatment for asymptomatic HIV persons. I ask that you do this because it makes economic sense and because it is the moral and humane thing to do.

Finally, no matter how much early intervention we provide, for many, if not most infected people, the onslaught of AIDS is inevitable. Ultimately, a person with AIDS will no longer be able to work and most will deplete their funds. These people face an incurable, wasting, debilitating disease and poverty.

They do and will turn to community-based organizations for assistance, but it will be impossible for AIDS Project Los Angeles or any other community-based organization to keep up with the projected growth of persons with AIDS. We cannot possibly raise the

funds from the private sector to sustain the growth that is projected. Other community-based organizations throughout the country face a similar struggle and a bleak future.

I implore you, the numbers will rise like a tidal wave. We cannot provide the vital services presently provided without government help. A natural disaster is looming before you among your constituents.

Let me leave you with one additional thought. Some day, God willing, there will be a cure. The more people we keep alive, the longer we sustain life, the more people will be there on that brilliant day when the cure is found.

Increasing the number of cured people returned to a happy, healthy and productive life on that brilliant day is in your hands. I beg you to act.

Thank you.

[The prepared statement of Mr. Wexler follows:]

#### STATEMENT OF DAVID WEXLER

I am speaking today on behalf of AIDS Project Los Angeles, the oldest and largest community-based AIDS service agency in Southern California. AIDS Project Los Angeles is currently meeting the needs of over 2,250 men, women and children with AIDS, representing 68 percent of the entire AIDS-diagnosed population of Los Angeles County. Our services include case management, mental health, emergency food, shelter, and transportation, dental and home health care, the Southern California Regional AIDS Hotline, insurance and public benefits counseling, a 300-member Buddy program, and, soon, long-term low-income housing. Over 100 paid staff and 1,100 active volunteers work at AIDS Project Los Angeles.

AIDS Project Los Angeles estimates that there are over 250 other community-based agencies which are helping to provide the broad spectrum of HIV-related service needs in Los Angeles County. Their services range from education, to surveillance, to testing and counseling, to preventive therapy, to emergency and long-term medical and social services. These agencies, along with APLA, strive to meet the needs of a population which is expanding at an alarming rate, and a public and governmental climate which, for reasons unknown to us, seems gradually to be slipping into the conviction that the worst of the AIDS crisis is somehow over.

I am here today to tell you that, for those of us working in community-based agencies in Los Angeles County, the AIDS crisis is most assuredly NOT over; in fact, without immediate emergency funding the future is catastrophic.

According to the Los Angeles County Strategic Plan for fiscal years 1990-91 through 1992-93, from which important elements of my testimony are drawn, as of April 1990, more than 9,000 persons in Los Angeles County had developed AIDS. The plan suggests that by the end of 1993, over 24,000 AIDS cases will have been diagnosed in Los Angeles County. Approximately 2,800 persons with AIDS are currently living in the County, but local government epidemiologists estimate that Los Angeles has an additional 109,000 HIV-infected individuals. By the end of 1992, it is estimated that approximately 13,000 HIV-infected individuals will have presenting symptoms requiring treatment, and that there will be at least 99,000 asymptomatic individuals in need of medical monitoring and preventive therapy in order to slow their progression to illness.

Furthermore, during the 1990-91 fiscal year, the cost of providing public sector outpatient care to these asymptomatic HIV-infected men and women for early intervention will be over \$177 million, and by the 1992-93 fiscal year, over \$186 million. The combined public and private sector cost in Los Angeles County for the full spectrum of medical and support services for HIV-infected populations, including mental health care, case management, housing, hospice, and home care, will be nearly \$840 million dollars in 1990-91, and close to \$1 billion dollars in 1992-93.

The health and social service system in Los Angeles County will need to more fully develop a plan to provide services to these HIV-infected populations in a coordinated and proactive manner. Such a plan will need to integrate medical services along a continuum of care from the time of testing positive for HIV infection to the time of needing extensive medical care in the end stages of AIDS. It must also coordinate human service delivery among the many public and community health and



human service agencies providing service in our area. This coordination and the necessary service development and integration need to build on the HRSA/RWJ demonstration grant activities which have provided the underpinnings for our current community-based service system. The expansion of those existing structures is absolutely necessary to insure the ability of Los Angeles County to meet the future needs posed by the growing HIV caseload.

The currently the missing link in the successful implementation of a continuum-based service plan—will be the provision of early intervention, monitoring, and access for asymptomatic HIV-positive individuals.

The Los Angeles County HIV Strategic Plan projects the need for AIDS services along a continuum of care based on the depletion of T-helper lymphocytes as a clinical index of progression to symptomatic illness. Under such a projection system, an estimate of the number of HIV-infected persons with particular T-cell counts drives the estimate of services needed; in the Los Angeles County Strategic Plan, the following three distinct divisions of T-cell level have been made: those T-cell counts below 200; those with counts between 200 and 500; and T-cell counts above 500.

Among those with T-cell counts below 200 are patients presenting symptoms and requiring hospitalization and/or extensive outpatient services. Among the HIV-infected who are still asymptomatic, the County estimates that at any given time, 30 percent will have T-cell counts below 200; 50 percent will have T-cell counts between 200 and 500; and 20 percent will have counts above 500. Over the next two and one-half years, individuals in the category of HIV-asymptomatic with T-cell counts under 200 will increase most dramatically, from 30,946 in 1990-91, to 52,746 by mid-1993. These individuals are precisely those who will be in greatest need of close medical monitoring and access to treatment therapies in order to extend the period of time prior to becoming symptomatic.

The case for expanding therapeutic strategies aimed at asymptomatic HIV-infected individuals is compelling. Epidemiologic data has demonstrated that, without adequate early intervention, a large percentage of persons infected with HIV will progress to end-stage AIDS. There is also powerful evidence that developing drugs such as AZT can effectively stop replication of the retrovirus, carrying the possibility that such drugs will conceivably decrease infectivity and eventually slow the spread of the epidemic. In addition, the steadily increasing incidence of nonopportunistic infections associated with the presence of HIV—syphilis, tuberculosis, and bacterial pneumonia—may be more effectively contained if effective antiretroviral agents are added to regimens in use for the primary treatment of these illnesses.

Our current problem is that the time in which we can still effectively intervene on behalf of asymptomatic HIV-infected individuals is running out. Studies in San Francisco demonstrate, for example, that approximately 80 percent of the homosexual and bisexual men who were infected with HIV between 1978 and 1987 acquired the virus by 1984. This suggests that a large segment of that HIV-infected population is now rapidly approaching the late stages of infection prior to developing AIDS. Since the beginning of the epidemic, the largest proportion of AIDS cases in Los Angeles County has consistently been among gay and bisexual men, even among ethnic minority cases, suggesting a similar impending closeness to full-blown AIDS in the near future on the part of a large percentage of our population.

The optimal plan for the provision of appropriate treatment to HIV-infected asymptomatic individuals would include providing semiannual monitoring but no AZT and pentamidine therapy to persons with T-cell counts over 500; for individuals with T-cell counts between 200 and 500, provision of weekly monitoring for the first three months, followed by monthly monitoring, and administration of AZT regimens; and the addition of pentamidine to individuals with T-cell counts under 200. It is estimated that only 50 percent of this third group will be able to tolerate AZT, and that 50 percent of those who can tolerate AZT will develop anemia. One-half of these will require blood transfusions, while the remaining half will receive the drug EPO.

The West Hollywood HIV Clinic and the Los Angeles County/USC Medical Center Los Angeles' existing key hubs for HIV-asymptomatic treatment currently provide monitoring and prophylaxis therapy to approximately 500 HIV-infected individuals on a regular basis. In order to meet the existing need of currently infected asymptomatic men and women in Los Angeles County who are not receiving treatment through private providers, it is estimated that the capacity for services would have to increase to 39,000 by mid-1991. Because early intervention for HIV-infected individuals has a direct correlation to a prolonged and qualitatively superior lifespan, it is imperative that these improvements to the system, radical as they are in terms of increase over existing expenditures, must be made immediately.

One out of every seventy residents in Los Angeles County, or 109,000 persons is estimated to be infected with HIV. Barring the infusion of the resources necessary to meet their care and treatment needs, we have every expectation that every one of these persons will eventually go on to develop AIDS. Not only will this catastrophe create an unprecedented crisis for both the public and private health care systems in our county, but it will precipitate untold suffering for the men, women, and children already infected or soon to be infected with HIV. Finally, we believe this is true not only for our own County of Los Angeles, but for all high-incidence metropolitan areas of the United States.

Mr. WAXMAN. Thank you very much, Mr. Wexler.  
Mr. Kelen.

#### STATEMENT OF GABOR D. KELEN

Mr. KELEN. Thank you, Mr. Chairman, members of the committee. My name is Gabe Kelen. I am a board-certified emergency physician at the Johns Hopkins Hospital and on faculty at the Johns Hopkins University School of Medicine.

I appreciate the opportunity to come before you and present some of the data regarding our patients in our Emergency Department in Baltimore. I am also in the unique position of thanking Mr. Silverman, because it was his organization that funded some of the studies that I will be presenting.

I think we are all familiar now with the huge numbers of AIDS cases that are being projected and somewhere in the neighborhood of 1 to 1½ million Americans with hidden infections. What may be less well known is that there are 80 million patient visits to emergency departments each year in this country, so a fair number of patients with HIV infection can be expected.

Those of us who work in emergency departments are legally and ethically bound to see every single patient who comes seeking our care. This has tremendous potential for overburdening our system as more and more patients with HIV infection come seeking our aid. This is particularly true for innercities and particularly true for those innercities with high seroprevalence of HIV.

This will affect everybody's care, not just those with HIV infection, but everybody who seeks emergency care.

Innercities serve those most at risk of HIV, particularly minorities and those with risk factors. Our particular situation is 75 percent of our patients are black and 22 percent have a risk factor, half of those being intravenous drug use. We have a disproportionate case load of patients who are relatively impecunious.

We know that the wave is coming. As Mr. Dannemeyer mentioned, just a few years ago, we had a 3 percent rate of HIV infection among our population, and now it is around 7.5 percent. Among young black males, the rate is actually closer to about 15 percent or so. While the majority are still currently asymptomatic and undiagnosed, we are seeing more and more patients with symptomatic HIV infection. A few years ago, we estimated that maybe only half a percentage of our census was from patients with HIV infection. Now it is around 2.5 percent who are symptomatic.

Johns Hopkins is a relatively unique situation, but our patients are probably reflective of those in innercities. We are designated a treatment center. We admit 50 percent of the city's AIDS patients and 40 percent for the entire State.



For those of you who happen to have the handout, if you can turn to page 8, I will just briefly review the characteristics of some of these patients.

Less than 40 percent actually have AIDS and just under 50 percent are still currently asymptomatic, and as these patients become symptomatic, a few will be defined as AIDS, but many will simply be what is currently designated as ARC and they may not qualify for Federal subsidies as it is currently designed.

Most of our patients are followed at Johns Hopkins, but at least a third are not followed by anybody at all. This, despite that we have a free clinic that is willing to see any patient who is infected, regardless of ability to pay.

Many of our patients are relatively sick and are admitted. Intravenous drug users, we are particularly worried about. We feel they represent relative recent infection. A few years ago, 19 percent of drug users were seropositive. Now we are up to 34 percent, almost a doubling.

Very few of them are being followed. Only around 50 percent are followed by a physician, despite this clinic, as compared, say, to 81 percent for those who are homosexual or bisexual. They are fairly used to using the emergency department for routine care and that is obvious from some of our data.

This has some problems for emergency department and for those of you are able to, if you could follow on page 9, on table I, I show you the breakdown of insurance status for the population that we show. The one on the right, the general emergency department population, is everybody who comes through the door. We already start with a fairly high load of Medicaid and self-paying patients.

If you look at the column next, all patients who have HIV infection, the load of Medicaid and nonpaying patients has increased. We are able to break that out in the first two columns. Those are asymptomatic, meaning those who will come to seek our care later, perhaps the worse payor status overall, a huge load of Medicaid and nonpaying patients. Forty percent, almost, for Medicaid and just under 50 percent for self-pay.

If we look a little closer at who these patients are on the next table, you can see that those who have IV drug use as their risk factor, a huge Medicaid load, 42 percent, and a little over 45 percent for those who are self-pay. Perhaps not surprisingly, if you follow on table 4, those without a source of care are the ones who are less likely to be able to pay at all.

If you turn to the next page, we are able to break out who uses the emergency department, based on the type of insurance that they have. People with private insurance tend not to use the emergency department too much. The most visits during our study time period was six. Those with Medicaid, patients visit up to 10 times, and those who are self-pay, have no other means to pay, visit us up to 15 times in a 10-month period.

This is relatively worrisome because innercities, as I mentioned, begin with a relatively poor payor mix. Our budgets are strained. Our particular situation is that we run a deficit. Medicaid and most States do not reimburse professional fees particularly well. For instance, most of our charges for a typical visit range from \$75

to \$125. Medicaid in our State reimburses professional fees at \$10.50.

By comparison, Medicare is somewhere around 50 percent and Blue Cross/Blue Shield and other private payors are closer to 80 percent.

Our overall collection rates range somewhere around 30 percent and you would not normally be able to make a living on that basis.

Let me just summarize—move to the recommendations and then I will finish with that.

I believe that methods must be found to ensure appropriate access for all AIDS patients. Sources of funding for the care of patients with HIV infections who are not otherwise able to pay for services must be found. Appropriate sources for their care must be found and this may include moving from specialist care to those in general practice and I believe that research should focus not just on drug use behavior among that risk group, but also on patterns of utilization of health service. When free clinics are available, they should make themselves available for that.

Thank you very much.

[Testimony resumes on p. 259.]

[The prepared statement of Mr. Kelen follows:]



## STATEMENT OF GABOR D. KELEN

Mr. chairman and members of the Committee. My name is Gabor D. Kelen, M.D. I am a board certified emergency physician at The Johns Hopkins Hospital and a faculty member of the Johns Hopkins University School of Medicine. I appreciate the opportunity to address the Committee, and present data from our studies regarding patients with HIV-1 infection who seek health care in our emergency department in Baltimore.

**BACKGROUND**

There have been approximately 120,000 cases of AIDS reported to the Centers for Disease Control (CDC) to date. Recent estimates indicate that there will be a total of 285,000 cases diagnosed by 1991, and 450,000 by 1993. It is estimated that there are another 1 to 1.5 million Americans who have asymptomatic and undiagnosed infections. With over 80 million patient visits to emergency departments in this country each year, the epidemic clearly has the potential for major impact on emergency services.

Americans are becoming used to seeking care in emergency departments. If plans to provide anticipated service needs for the increasing number of patients with symptomatic HIV-1 infection are not made and in place in the near future, emergency departments will likely take the brunt. Emergency departments are ethically and legally bound to evaluate all patients seeking care, and render necessary care. Should emergency departments become overburdened, the result will be a decrease in quality of care, a decrease in services, or both. This will affect not only HIV-1 infected patients but all patients who seek emergency care.

Already, the impact of the HIV epidemic is increasingly being felt by inner-city emergency departments in areas with high prevalence of HIV-1. In 1986, 3.0% of patients

critically ill and injured presenting to the Johns Hopkins Hospital Main Emergency Department had undiagnosed HIV infection. In 1988, 6.0% of the general emergency department patient population were shown to have HIV infection. Currently, 7.5% of the patients have HIV infection. Most of these patients (4%) have undiagnosed asymptomatic infection, although the proportion of symptomatic patients is steadily increasing. In 1986 less than 0.5% of emergency department patients had symptomatic HIV infection. By 1987, 1.2% of the emergency department patients had known HIV infection. More recently, we estimate that 2.5% of our patient population has known HIV infection. Our data indicates this proportion is likely to continue to increase as many individuals at risk of acquiring HIV use the emergency department as a source of care.

### THE JOHNS HOPKINS EXPERIENCE

#### Patient Population

The Johns Hopkins Hospital (JHH) is a designated AIDS treatment center. More than 50% of all AIDS admissions in Baltimore City and 40% of AIDS admission in Maryland are to the Johns Hopkins Hospital (Maryland State AIDS Program). There have been 1334 cases of AIDS reported in SMSA Baltimore (528 live), and 2326 cases for the state of Maryland (944 alive) through to January 1990.

The emergency department serves a predominantly indigent minority population in a socioeconomically disadvantaged area, although many patients from greater Baltimore also seek our services. Annual census of the emergency department is approximately 55,000 patient visits. Approximately 75% of the patients are black. Among our general emergency department patient population 22% have been shown to have at least one risk factor for HIV. Half of these (11%) are intravenous drug users.

Minorities among our emergency department population are being particularly affected by the epidemic. This is reflective of national statistics. Blacks in our population are more than twice as likely to be infected with HIV compared to whites. Young black males approach a seroprevalence of 16%. Although the infection is predominantly concentrated among this group, we have found HIV infection among all races, both sexes, and distributed over a wide age range.

The rate of new infections among intravenous drug users in Baltimore is increasing at an alarming rate. In 1987, 19% of drug users had unrecognized, HIV infection. By 1989, 34% of all drug users seeking emergency care had undiagnosed infection. The overall prevalence of HIV-1 infection among all drug users (diagnosed and not diagnosed) in our population is even higher. Evidence shows that patients with this risk factor, use emergency departments as a primary source of care.

#### Utilization of Emergency Services by HIV-1 Infected Patients

Data available from a 10 month consecutive period in 1988 (March to December) show that there were 497 visits from 299 individual patients with a previously established diagnoses of HIV infection (Table 1). This is an average of 1.7 visits per patient. However, 58 patients (19.3%) had 4 or more visits during this time. There were 264 (53%) patients visits with symptomatic HIV infection. Of these, 187 visits were from 106 individuals who carried a diagnosis of true AIDS.

During the 10 month period, 106 individual patients with AIDS sought emergency services at Johns Hopkins. Of these, 96 lived within SMSA Baltimore. There were approximately 317 live patients with AIDS in Baltimore in 1988. Thus, during this 10 month period more than 30%, of the known AIDS patients in Baltimore, sought emergency

care at least once at Johns Hopkins.

The majority of our patients (68%) have a regular source of care (Table 1). However, 66% of the visits occurred when the usual source of care was unavailable. Further, at least 32% of visits among those previously asymptomatic were the first manifestations of HIV infection to be brought to medical attention. Although there is an AIDS clinic at Johns Hopkins that provides care to patients regardless of ability to pay, only 55% of intravenous drug users in this series had a regular source of care compared to 81% for those with homosexual/bisexual risk. The reasons for this are not clear. However, homosexual patients tend to be white, middle-class people who are relative medically sophisticated, while intravenous drug users are less versatile in knowing the medical system and have become used to ease of accessibility and quality of care in emergency departments.

Only 36% of the intravenous drug users sought care for reasons related to HIV infection compared to 87% for those with homosexual/bisexual risk. This data can be interpreted in two ways. Considering the rapid rise in infection rates for intravenous drug users, this risk group likely represents more recently acquired infection. The majority of these are currently asymptomatic. Another interpretation is that intravenous drug users access emergency departments as a routine source of care for many of their health care problems. This is a generally accepted tenet. Regardless of the interpretation, it is clear that there will be large increases in the numbers of intravenous drug users with symptomatic HIV infection seeking health services in the not so distant future.

The potential increase in utilization is worrisome. Our data indicate that the majority of HIV infected patients have either no insurance or have Medicaid. Medicaid in many states reimburses outpatient costs poorly, particularly professional fees. Among our



general patient population, 58% have Medicaid (20%) or no health insurance (38%). By comparison 76% of HIV infected patients have Medicaid (35%) or no insurance (41%) (Table 3). While 18% of the general patient population is covered by Medicare, less than 1% of the HIV infected patients are.

What is particularly worrisome is that those who are currently infected with HIV-1 but asymptomatic, have an even worse payor profile. Over 85% of these patients have no source of funding (47%) or only Medicaid (38%). Similarly, 88% of HIV-1 infected intravenous drug users have insufficient source of funding (Table 4), the very group that will increasingly need to utilize health services for HIV related problems in the near future.

As expected there is a relationship between payor status and having a regular source of care (Table 4). Patients with a regular source of care were more likely to have private or third party insurance (27%) compared to those that were not followed (12%). Further, 55% of those who did not have a regular source of care, had no insurance whatsoever.

There appears to be a relationship between payor status and frequency of use of emergency services (Figure 1). Most patients with private or third party insurance had only one or two visits during the 10 month period. Patients with Medicaid had up to 9 visits. A few patients without any insurance had up to 15 visits.

We believe that these statistics are generally reflective of other inner-cities. Clearly payor status of most HIV infected patients is problematic and these data indicate that it will remain so for the next wave who become symptomatic from their HIV infection. Emergency care is an integral and essential part of the medical services required for AIDS patients, but should not be a substitute for lack of access to ongoing and longitudinal primary care. This is not a problem in our immediate locale, since we have an organized outpatient program and a clinic that follows any HIV infected patient regardless of ability

to pay. However, in other centers or cities less well organized or with less resources and commitment to AIDS care than Johns Hopkins, the emergency department may be the only source of care readily available to these patients.

#### Other Impact on Emergency Services

Inner city emergency services often have negative financial balances because of the overall payor mix of the populations they serve. The hospital through various means is usually the source that subsidizes emergency care. Because of the impecunious nature of departments delivering emergency care in the inner-city, budgets are stretched to the limit. This has impact on equipment purchase and maintenance, hiring practices, salaries, and staff morale. The high load of Medicaid and Self Pay patients strains this situation. For example, Medicaid reimbursement for professional fee charges (typically \$75 to \$125) is about \$10.50. By comparison, Medicare and Private insurers reimburse at about 50% and 80% respectively. Based on the data presented above, the more symptomatic HIV infected patients utilize emergency services, the greater the stress on the financial health of the department. This has the potential to affect care for all patients.

#### Impact on Other Hospital Services

Admissions to the Hospital for AIDS related illness has increased from 333 in (fiscal year) 1987 to 659 in (fiscal year) 1989. The emergency department is an important conduit for AIDS related admissions to the hospital. There were 210 admissions during this time of our data collection, accounting for approximately 44% of AIDS related admissions to the hospital.

Although the number of admissions have increased, the daily census is leveling off at about 20 per day. The main reason for this success is the strong integrated care offered at Hopkins, and the shift in emphasis from inpatient management to outpatient management. For example clinic visits have increased from 1,999 in 1987 to 6,115 in 1989.

The other impact relates to hidden costs. There has been a great push to protect health care workers from potential infection acquired while in the line of duty at work. The main thrust of this protection is Universal Precautions. Unfortunately, implementing Universal Precautions are very expensive. For example the cost of providing gloves alone has increased from \$309,000 to \$1,028,142. Part of this is glove use itself, but a large component is increased cost. Whereas glove use did not increase from 1988 to 1989, the cost of providing them doubled due to increased price alone. If Universal precautions were to be rigorously followed, the costs would be substantially more.

### RECOMMENDATIONS

1. Methods must be found to ensure access to appropriate care for all patients. Because of the special problems inherent with AIDS patients this is particularly true.
2. Sources of funding the care of patients with HIV infection who are not otherwise able to pay for services must be found. This is particularly true of areas with high seroprevalence which tend to be within inner-cities.
3. Appropriate sources of care must be available for the care of AIDS patients, so that more costly emergency care is not inappropriately utilized simply out of convenience.
4. Research should focus on behavior change among intravenous drug users, not only for their drug problem, but also on patterns of utilization of health services.

Table 1. Characteristics of 497 Emergency Department Visits by Patients with Known HIV Infection (March 1989 to December 1989)

Characteristic	Numbers (%)
<b>Age</b>	
< 26	37 (7%)
26-35	256 (52%)
36-45	158 (32%)
46-55	34 (7%)
> 55	11 (2%)
<b>Race</b>	
Black	378 (76%)
White	116 (23%)
Other	3 (1%)
<b>Sex</b>	
Male	384 (77%)
Female	113 (23%)
<b>HIV Classification</b>	
AIDS	187 (38%)
ARC	77 (15%)
Asymptomatic	233 (47%)
<b>Risk (%)Factor</b>	
IVDU	253 (51%)
Homosexual	129 (26%)
IVDU and Homosexual	18 (4%)
Heterosexual Contact	9 (2%)
Transfusion Related	11 (2%)
Unclear	77 (15%)
<b>Source of Care</b>	
Johns Hopkins	287 (58%)
Other Centers	49 (10%)
None Known	161 (32%)
<b>Disposition</b>	
Admitted	210 (42%)
Discharged	270 (54%)
Left Against Advice (AMA)	17 (3%)
<b>Payor Status</b>	
Private/Third Party/HMO	110 (22%)
Medicare	3 (1%)
Medicaid	174 (35%)
Self Pay	202 (41%)
Jail	8 (2%)
<b>TOTAL</b>	497 (100%)



**Table 2. Health Insurance Status Among 497 Symptomatic and Asymptomatic HIV-1 Infected Patients Seeking Care at the Johns Hopkins Hospital Main Emergency Department (March to December 1988)**

	Symptomatic HIV Infection N (%)	Asymptomatic HIV Infection N (%)	All HIV Patients N (%)	General Emergency Population
Third Party or Private	83 (32%)	35 (15%)	118 (24%)	24%
Medicare	2 (1%)	1 (<1%)	3 (<1%)	18%
Medicaid	84 (33%)	90 (38%)	174 (35%)	20%
None	89 (34%)	113 (47%)	202 (41%)	38%
<b>TOTAL</b>	<b>258 (100%)</b>	<b>239 (100%)</b>	<b>497 (100%)</b>	

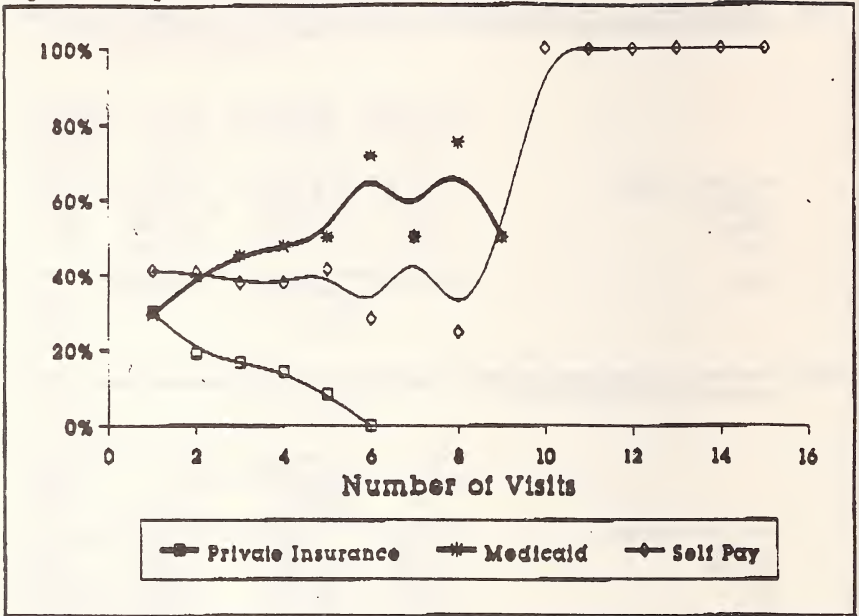
**Table 3. Health Insurance Status Among 497 HIV-1 Infected Patients Emergency Department Patients by Risk Factor (March to December 1988)**

	IVDU Risk N (%)	Homosexual/ Bisexual Risk N (%)	Other Risk N (%)	All HIV Patients N (%)
Third Party or Private	24 (10%)	54 (42%)	33 (28%)	110 (22%)
Medicare	2 (1%)	0 (0%)	1 (1%)	3 (1%)
Medicaid	107 (42%)	29 (22%)	37 (32%)	174 (35%)
None	116 (46%)	44 (34%)	42 (36%)	202 (41%)
Jail	4 (2%)	2 (2%)	2 (2%)	8 (2%)
<b>TOTAL</b>	<b>253 (100%)</b>	<b>129 (100%)</b>	<b>116 (100%)</b>	<b>497 (100%)</b>

**Table 4. Health Insurance Status Among 497 HIV-1 Infected Patients Emergency Department Patients by Regular Source of Care (March to December 1988)**

	Regular Care N (%)	No Source Of Care N (%)
Third Party or Private	91 (27%)	19 (12%)
Medicare	2 (<1%)	1 (<1%)
Medicaid	127 (38%)	47 (29%)
None	114 (34%)	88 (55%)
Jail	2 (<1%)	6 (4%)
<b>TOTAL</b>	<b>336 (100%)</b>	<b>161 (100%)</b>

Figure 1. Proportion of Visits by Insurance Status



Mr. WAXMAN. Thank you very much, Dr. Kelen.  
Mr. Smith.

# STATEMENT OF MARK D. SMITH

Mr. SMITH. Thank you, Mr. Chairman.

If we are engaged in full disclosure, I suppose I should disclose that I have an MBA, but it is with my physician hat that I am here this morning.

I am a physician who has been involved in clinical research, administrative and teaching aspects of HIV disease since I was an intern at San Francisco General in 1983. I have served as the director of the Philadelphia Commission on AIDS and as an advisor to Governor Casey in Pennsylvania. I now serve as the associate director of the AIDS Service at Johns Hopkins. I run that free clinic that Dr. Kelen talked about.

I have given you some written testimony. I will not read it, but would like to make four basic points this morning.

The first is that early intervention makes a difference. The second is that people don't have access to early intervention. The third is that we have a series and a system of perverse incentives that we must overcome. The fourth is some comments about why I think this legislation would help.

The payoff is beginning. The payoff in terms of the millions of dollars of Federal and private research money, the time invested, the generosity of those patients who have been willing to serve as research subjects over the year. The payoff from that research is beginning to happen.

So we now know that Zidovudine can prolong people's lives, can delay their progression to AIDS. We know that various forms of prophylaxis against pneumocystis carinii pneumonia can delay or retard or even completely prevent this infection. We know that appropriate screening for diseases such as tuberculosis and syphilis, appropriate immunizations for diseases such as influenza and pneumococcal disease can reduce the burden of mortality and morbidity in people with HIV infections. So we know that that works.

The second point, however, is that it is not available to many people. By way of example, at Johns Hopkins, we admitted 172 patients with pneumocystis pneumonia in the course of the last 16 months. Most of those patients were not failures of preventive therapy; most of those patients were failures of the system that is not providing preventive therapy to them.

We daily see patients who ought to be on Zidovudine who are not. We daily see patients who are admitted for pneumococcal sepsis for whom that illness and the expense associated with that admission could have been avoided, had they been properly treated.

So while we have a payoff from the clinical research, we don't yet have the capacity to apply that payoff in practice.

The third point is about perverse incentives. Almost every day, one of our providers in our clinic is faced with a request from a patient to declare him or her permanently and totally disabled. This often includes patients who are working, who want to work, who need to work, but for whom the only access to eligibility to

pay for their medications and their visits is to be declared totally and permanently disabled. It is kind of a perverse incentive.

We will present to the International AIDS Conference in San Francisco, if there is an International AIDS Conference in San Francisco, we will present data that demonstrates that inhaled pentamidine, as expensive as it is, is still cost-effective for insurers and would be even if its price were substantially higher than it is now. Clearly, the Federal Government is the largest insurer of medical care, and yet, our reimbursement system, while it will pay \$14,000 for an inpatient admission—at least in our institution—for pneumocystis, has a difficult time adequately compensating physicians and institutions to provide the outpatient care that would prevent perhaps as many as 85 percent of those inpatient admissions.

So we have a system of perverse incentives that rewards, in some way, visits to Dr. Kelen's emergency room and admissions to our inpatient unit, but does not adequately reimburse outpatient care.

At the back of my written testimony, you will see a series of graphs that is, I think, testimony to the burden of care that Johns Hopkins is now providing. You see that our inpatient admissions, our inpatient census, our outpatient visits rise every year and yet our length of stay in the inpatient unit decreases every year.

The reason it decreases is largely because we are much more aggressive in using outpatient diagnostic and therapeutic maneuvers than we used to be. But I have to tell you that we lose more and more money every year in the outpatient setting because it is particularly outpatient services that are not well reimbursed.

The last point is a couple of comments on how I think this bill would help. There are two categories of providers with regard to HIV care. There are a few high-volume providers. You know, from the work of Dennis Andrulis and others, that there are about 5 percent of the hospitals in this country who take care of the vast majority of people with AIDS. The same thing is true for physicians and other outpatient facilities.

Johns Hopkins is clearly among those high-volume providers. I think those high-volume providers need relief. They need financial assistance to be able to continue to not only shoulder that burden, but shoulder the vastly increased burden that will be needed by more people.

I think Medicaid will help that, but if you look at the last graph on my chart, it is worth pointing out that Medicaid reimbursement for outpatient, nonprocedural care is not much better than no reimbursement at all, and therefore, I also support a system of special grants to assist getting new providers—that is, low-volume providers—involved in this care because those of us who are already involved clearly will not be able to shoulder the task that is coming.

Thank you.

[Testimony resumes on p. 272.]

[The prepared statement of Mr. Smith follows:]



## Testimony before the House Subcommittee on Health

April 19, 1990

Mark D. Smith, MD, MBA

Associate Director, AIDS Service  
Johns Hopkins School of Medicine

Good morning, Mr. Chairman and ladies and gentlemen. My name is Mark Smith; I am a physician with several years of experience in clinical, administrative, and research roles in the AIDS epidemic, and currently serve on the faculties of the Johns Hopkins Schools of Medicine and Public Health and as the Associate Director of the AIDS Service at Johns Hopkins Hospital in Baltimore. I thank you for the opportunity to testify on this important matter.

When the epidemic of HIV disease was first being recognized and described, a surveillance definition of a clinical syndrome - the Acquired Immune Deficiency Syndrome - was developed by the Centers for Disease Control. A list of specific infections and cancers was developed; this list, subsequently revised, actually constitutes what we now recognize as the last stages of HIV infection.

We are here this morning to discuss intervention in the early stages of this infection; intervention which will allow people infected with HIV to live longer and live better; intervention which we hope will allow them to live until we have more definitive therapies to offer.

There is now convincing evidence that early interventions can make a difference; three areas of need stand out:

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1. **Anti-viral therapy;** Zidovudine ("AZT") has been shown to improve survival in patients with both advanced and moderate immunosuppression, whether or not they have symptoms. Other antiviral drugs are also undergoing testing. These drugs are not cheap. Patients need access to the drugs themselves and to a system of primary care which can monitor them while taking such drugs.

2. **Prevention of ("prophylaxis against") pneumocystis carinii pneumonia,** an opportunistic infection which is the leading cause of mortality, morbidity, and health care expenditures in HIV - infected persons in the United States. Several drugs, given orally or in inhaled form, can reduce, delay, or possibly prevent the occurrence or recurrence of this disease in patients with evidence of advanced immunosuppression.

3. **Primary care services;** The two areas mentioned - antiviral therapy and pneumocystis prophylaxis - should be performed in a context - attention to primary care. Not only are there other early intervention services which are important (examples are screening for and treatment of tuberculosis and syphilis, and routine immunizations against influenza and pneumococcus), but I believe that the potential to reduce transmission of HIV by behavioral change among those infected will often require ongoing supportive relationships to encourage and reinforce such change.

So the good news is that we have much more to offer our patients than we did even two years ago. The bad news is that the vast majority of HIV-infected Americans are not benefiting from this scientific knowledge, even if they know or think that they are.

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positive (let alone those who don't suspect). And the number of providers actively engaged in HIV care will have to be dramatically increased if those infected are to have access to services.

We at Johns Hopkins have a good deal of experience in caring for people with advanced HIV disease - we care for about 1/2 of all the AIDS patient in the state of Maryland. Most of the individuals using these facilities are symptomatic - many have advanced disease. Although our caseload, and thus our inpatient census, continues to rise, our length of inpatient stay has fallen for each of the last 4 years, mainly because of improved use of outpatient facilities and more intensive diagnostic and therapeutic efforts in the outpatient setting (See figures 1-4). The fact is, however, that such increase intensity is not reimbursed; neither is the enormous intensity of social supports which our patients need.

We also perform early intervention. Our inhaled pentamidine clinic, for instance has served 318 people so far - over half of these patients are receiving pentamidine to prevent pneumocystis pneumonia not because they have had a prior episode, but because early HIV and T-cell testing and evaluation has identified them as being at high risk.

Under a contract with the state of Maryland, we operate an adult HIV Diagnostic Evaluation Unit (DEU) which performs state-of-the-art medical and psychosocial assessment on HIV-infected persons from around the state. The DEU has seen over 400 new patients in the last year. 65% of these patients were found, after evaluation, to have an indication for some medical therapy - ZDV, PCP prophylaxis, or both. But the biggest drawback to this system of

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expert evaluation and subsequent referral to community resources is that there are very few community resources - about 70% of the patients will, after evaluation, be followed in our own hospital-based clinic.

We have admitted 172 patient to the Johns Hopkins Hospital in the last year with a diagnosis of pneumocystis carinii pneumonia. While some of those cases represented a failure of preventive medicines, the vast majority represented a failure of the system which ought to be providing prophylaxis and isn't. The efforts to prevent this disease not only make medical and human sense, they also make financial sense as well, since each admission for PCP results in charges of almost \$14,000. At the International AIDS Conference in San Francisco we will present work which demonstrates that inhaled pentamidine, as expensive as it is, would still be a cost-effective strategy for insurers even if its cost were far higher than it is. And the federal government through Medicaid, is by far the largest insurer of HIV medical care.

Our institution has attracted a large number of patients both because of its extensive research program and because years ago its leadership made a commitment to be a leader in clinical care of HIV, despite the financial burden that such a commitment entails. In this, I believe that we are representative of that small percentage of American hospitals, clinics, and physicians who provide the large majority of HIV care at this time. As we know from the work of Dennis Andrulis and others, they are increasingly feeling the financial and operational strains of shouldering this burden. Some are public hospitals: Parkland in Dallas; Bellevue,



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Harlem, and Kings County Hospitals in New York; Boston City; Cook County; Miami and San Francisco General. Others, like Johns Hopkins, do not receive direct public subsidy but have, because of their location, their mission, or their expertise, risen to this challenge: Newark Children's; Columbia Presbyterian. These institutions and their associated physicians need relief, and I believe that the extension of Medicaid to cover less-symptomatic persons will principally benefit them - high-volume providers.

Medicaid eligibility will not, I think, substantially increase the pool of providers willing to see these patients, because for outpatient, non-procedural care, Medicaid is hardly better than no insurance at all (See attached figure). Therefore, while I fully support the proposed legislation, I think that it highlights a pressing need which is within your committee's purview: Medicaid reform not just for AIDS, but overall. I am not directly affected by Medicaid reimbursement rates, but I am sympathetic to my colleagues in private practice, some of whom, I believe, would like to care for more HIV and other Medicaid patients, but who do not feel that they can afford to do so. In my own state, Maryland, the Medicaid Administration is to be commended for pursuing a number of creative and innovative steps to improve the situation (both for AIDS patients and others) but Maryland is not the rest of the country, and the most creative of state officials can do little without stronger Federal commitment. I believe that the proposed supplemental grant programs will have a greater effect in inducing new potential providers to render the needed care.

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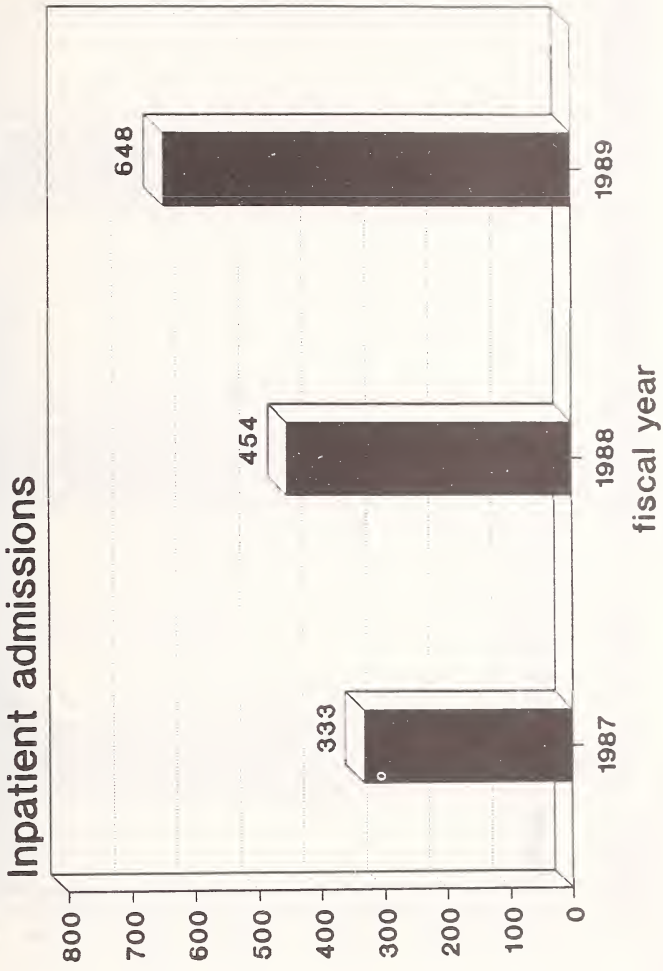
As members of the Subcommittee on Health you know as well as I that our health care system is filled with irrationalities and "Catch -22's". Nowhere, however, is this more apparent than in the current reimbursement system for HIV, in which patients with advanced disease have relatively expensive treatments paid for, but less ill patients, who could have serious disease averted or delayed, find it difficult to pay for these early interventions. Our providers are daily confronted with requests to declare "permanently and totally disabled" people who are not - people who are often working and want to continue to work, but who find themselves in a system with perverse incentives not to work in order to be able to have one's medical bills and prescriptions paid for.

I submit that there are two main areas in which the current system is inadequate to do the needed job in early intervention. The shortage of providers trained and willing to care for people with HIV infection; and the inadequacy of our health insurance system to pay for their care. These two problems are clearly linked, since part (though not all) of the reluctance of physicians and institutional providers to take on a greater role in HIV care is their unwillingness to go broke in doing so.

I hope that the passage of this legislation will contribute to providing the economic wherewithal to implement discoveries we are making in the early treatment of HIV disease. It is an area in which improved quality of care and decreased cost can simultaneously be served.

*Figure 1*

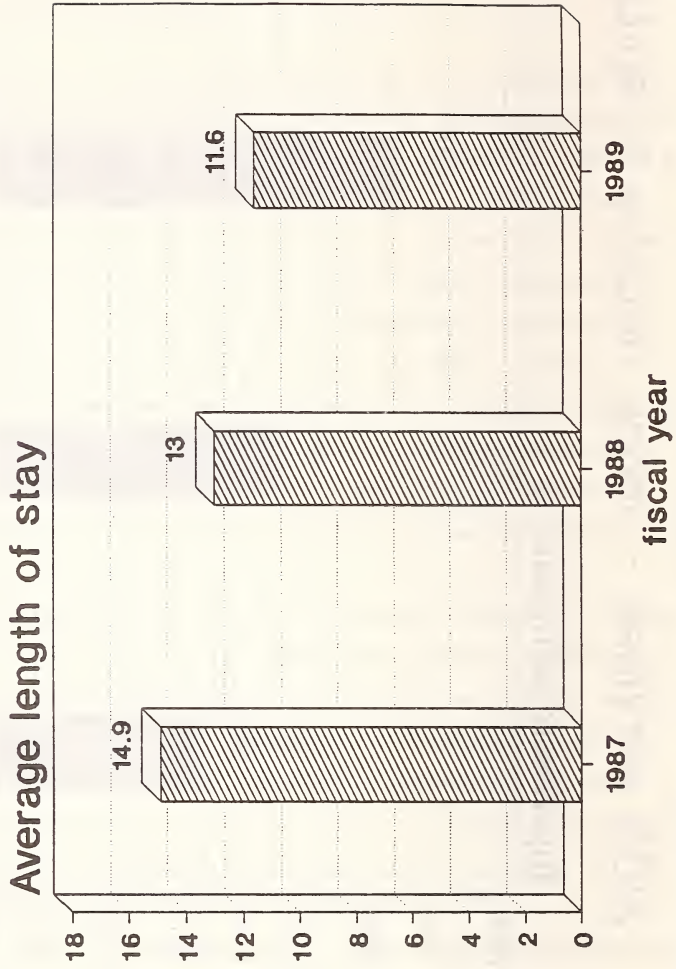
## AIDS services - Johns Hopkins Hospital



Mark D. Smith, M.D.

*Figure 2*

## AIDS services - Johns Hopkins Hospital



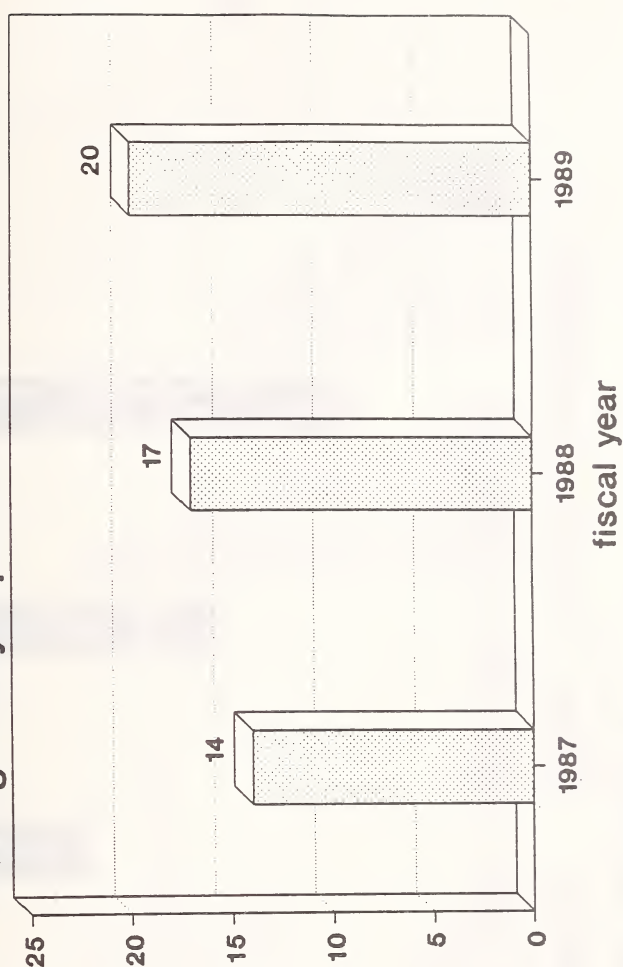
Mark D. Smith, M.D.



Figure 3

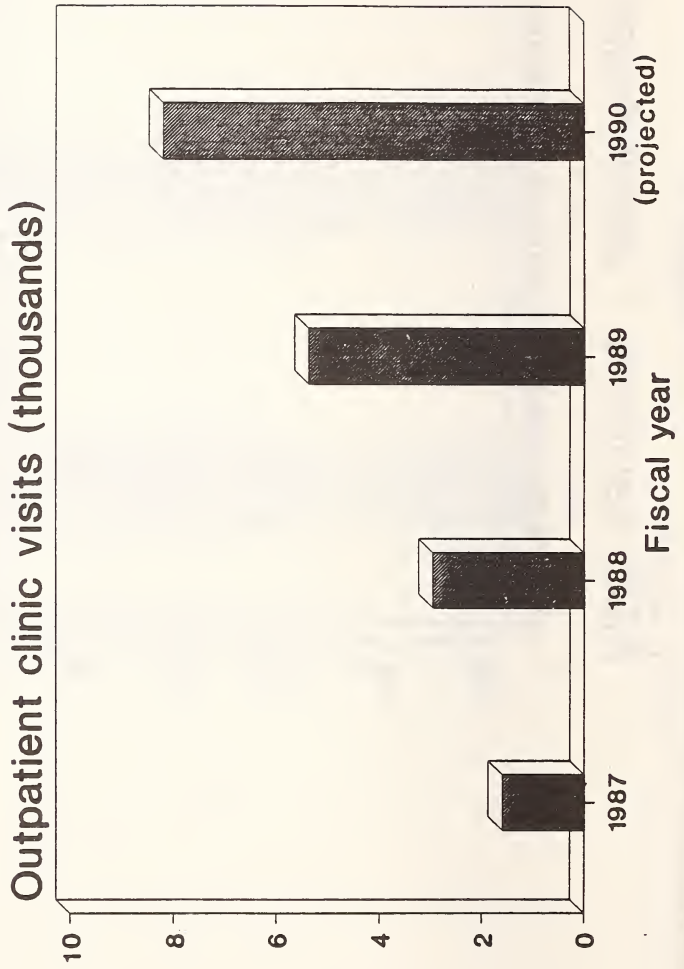
## AIDS services - Johns Hopkins Hospital

Average daily inpatient census



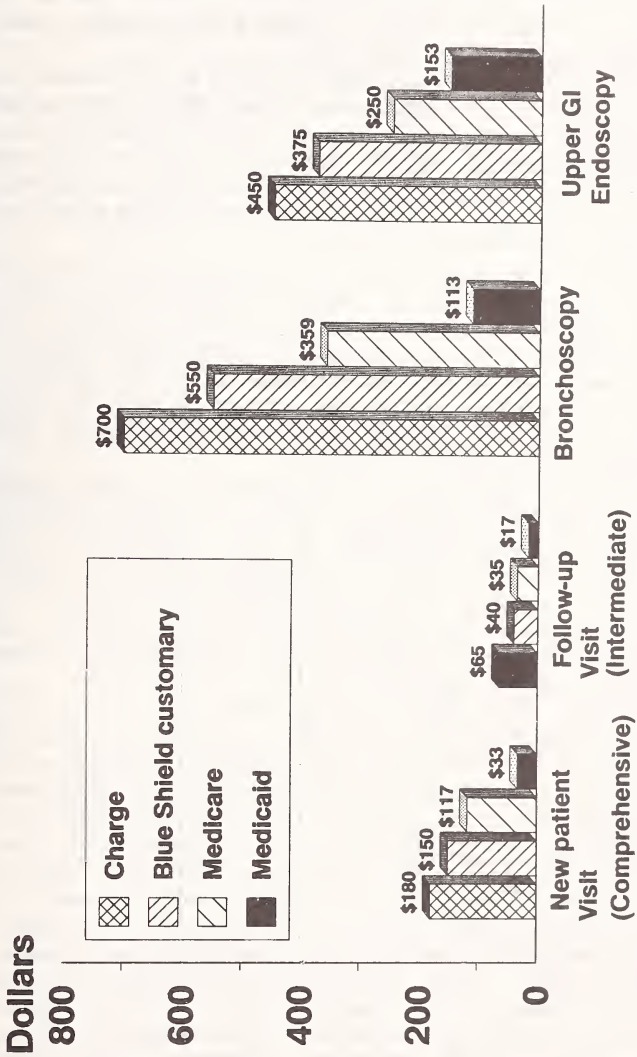
Mark D. Smith, M.D.

Figure 4  
AIDS services - Johns Hopkins Hospital



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# Maryland Charges and payments by insurer - 1989



Mr. WAXMAN. Thank you very much.  
Dr. Silverman.

#### STATEMENT OF MERVYN F. SILVERMAN

Mr. SILVERMAN. Mr. Chairman, I am Dr. Silverman, president of the American Foundation for AIDS Research and director of the Robert Woods Johnson Foundation, AIDS Health Services Program, and senior technical advisor to the Academy for Educational Developments, AIDS Program.

I am grateful for this opportunity to testify before you today, and in particular, Mr. Chairman, I would like to take this opportunity to commend and thank you and your committee for your strong record in fighting AIDS, and especially, Mr. Chairman, I think when the history of the fight against AIDS is written, the compassion, the courage and the leadership you have shown will be an important chapter in that history.

I have come today to talk to you about two very important initiatives currently before the House, the AIDS Prevention Act and the Medicaid AIDS and HIV Amendments Act. Both of these bills are of fundamental importance in the fight against AIDS. Simply put, if enacted, these bills will greatly improve AIDS-related health care and increase nationwide access to recently developed treatments that have proven effective in slowing the development of AIDS in those who are infected.

AIDS research has made great strides since this disease was first identified. In fact, we have learned more about this disease in a shorter period of time than any other disease in the history of humankind. The virus, HIV, that causes AIDS, has been discovered and we are learning more and more about how this virus attacks and eventually destroys the body's immune system, leaving the infected person highly susceptible to many common illnesses, known as opportunistic infections.

We now know that a person infected with HIV may not develop any serious symptoms of AIDS for as many as 8 to 12 years after being infected with the virus. During this time, an HIV-infected person will likely feel perfectly healthy, but blood tests will reveal a steady decline in the immune system, specifically in the number of vital infection-fighting blood cells known as T4-cells.

As the immune system declines, the body becomes more and more susceptible to opportunistic infections, many of which can prove deadly. With the help of our intensive research efforts, we have discovered drugs that can slow this steady decline of T-cells in HIV-infected people. We have also developed treatments that can prevent many of the deadly opportunistic infections that attack and kill people with depressed immune systems. These new treatments, as we have heard, are known as early interventions and they are enabling HIV-infected people to live longer and more productive lives.

More importantly, these new treatments are preventing very serious opportunistic infections that previously required costly and scarce hospital beds to treat. In short, early intervention makes good medical sense because it improves and prolongs life.



But just as importantly, early intervention also makes good economic sense. Although American research has made early intervention possible, it is a tragic fact that the American health care system has not yet been able to make it available to all those who need it. It is incredible that in this country of plenty that people are dying because they don't have access to these important medications.

There are two major reasons for this. First, the AIDS epidemic is growing so quickly that it has seriously compromised the ability of our Nation's health care system to meet demand for AIDS-related health care; and second, this vital early intervention treatment is presently unavailable under the current rules for Medicaid eligibility. The two bills presently before the House are specifically designed to correct these two problems.

The first bill, the AIDS Prevention Act, will provide emergency assistance to the cities that have been most severely affected by the AIDS crisis. This bill also includes specific grants for HIV testing, counseling and early intervention. With the number of AIDS cases expected to more than double in the next 2 years, this kind of emergency assistance is essential in order to sustain our Nation's health care system and maintain an adequate level of care for all persons infected with HIV.

The second bill, the Medicaid AIDS and HIV Amendments Act, will correct an ironic and extremely costly anomaly in our current system. Medicaid will, of course, pay for very costly hospital beds for AIDS patients who are already very sick, but against all common sense, Medicaid currently will not pay for the early intervention treatments that could prevent illness in the first place and avoid the need for expensive hospital care.

According to the current rules of Medicaid eligibility, HIV-infected people, even those with immune systems that have declined to the point where they are at risk for very—at very high risk for developing serious opportunistic infections, they are still not yet sick enough to qualify for Medicaid. A person is only eligible for treatment, such as early intervention, once they have already developed the illness that early intervention could prevent.

Current Medicaid practice is costly, inhumane and makes no medical sense. The Medicaid AIDS and HIV Amendments Act is the right answer. This bill will provide wider access to early intervention treatments that can prolong and improve the productive life of HIV-infected people.

As is often the case in medicine, a dollar of prevention today will save many dollars in the future. The Medicaid AIDS and HIV Amendments Act simply incorporates this sound, longstanding policy of preventive health care.

In closing, I would like to again emphasize the critical importance of both the AIDS Prevention Act and the Medicaid AIDS and HIV Amendments Act. Our government must be guided by two principles in this epidemic: The first is compassion for those who are suffering; and the second is fiscal responsibility so that we know our funds will be spent where they do the most good. These two bills provide you with the opportunity to pursue both goals at once, and with all my heart, I urge you to seize this opportunity and to make it happen.

Thank you.

Mr. WAXMAN. Thank you very much, Dr. Silverman, for your testimony. Let me start off asking Mr. Grant a question.

You have been very fortunate in getting access to some very expensive treatments. Do most people have such luck?

Mr. GRANT. No.

Mr. WAXMAN. Are government-funded programs necessary to assure access to such treatment?

Mr. GRANT. I believe they are. I have, as I said, continued to work and I have insurance. I have been able to take advantage of that as well as pay for some of the drugs that are not covered by my insurance policies.

Mr. WAXMAN. The administrations, both the Reagan administration and the Bush administration, said that AIDS health care services are not the responsibility of the Federal Government, but instead, something we should depend on State governments to pay for. Has the State of New York met the needs for AIDS early intervention services? Is there aerosol pentamidine provided to all the New Yorkers who need it? How about AZT?

Mr. GRANT. I don't believe so. I am not totally familiar with what is happening there, but I don't see it happening. I know that many of my friends with AIDS are not—and HIV positive others, are not having—do not have access to either pentamidine, aerosolized pentamidine, or AZT.

Mr. WAXMAN. Mr. Wexler, APLA now provides a large part of AIDS health care services to Los Angeles and for that, we all owe you a debt. We want to thank you for your work and for your dedication. You have laid out a clear description of what Los Angeles is going to go through, going through now and what is going to happen in the future. The projection of going from 500 patients in treatment to 39,000 is overwhelming.

You know that we will work to pass legislation to help meet those needs, but tell me, who will provide early intervention health care services if this legislation doesn't pass or isn't funded?

Mr. WEXLER. There is no one stepping up to the bar. I don't see who is going to provide for early intervention. Community-based organizations are not able to do so. We are trying to do so in testing in Los Angeles and the West Hollywood Clinic at USC, but the numbers are staggering and I cannot see it being done.

Mr. WAXMAN. If they don't get early intervention treatment, undoubtedly they are going to end up with full-blown AIDS and all the problems and end up getting hospital care under Medicaid or from the county system.

Mr. WEXLER. Without question, Mr. Waxman, they will end up sick, in the hospital and broke. The Federal Government will foot the bill. And the bill will be high.

Mr. WAXMAN. How much assistance do you get now from Los Angeles County for your work?

Mr. WEXLER. Thirty percent of our budget comes from either the State or the county and these are generally on grants. Seventy percent of our budget is raised from private sources. That is a lot of money, Congressman. That is a great deal of money that we have to raise and it is far more than we ever thought we would be able to raise.



I cannot see how that amount is going to increase in order to take care of the patient load that we see is coming.

Mr. WAXMAN. Under the terms of the emergency assistance legislation that is now being considered in the Senate, and that is included as part of H.R. 4470, the relief money for those areas with large impact of AIDS cases would most likely go to the board of supervisors of the county. Do you think that the board is likely to use that money to help APLA and other community groups to provide the health and social services that will be needed?

Mr. WEXLER. Not as presently constituted, no.

Mr. WAXMAN. Dr. Smith, the CDC has estimated that only a small portion of the infected people in the United States know that they are infected. Now that there are early intervention treatments, if such treatments are made accessible, either through Medicaid or through grants, do you believe more people will come forward for counseling, testing and treatment?

Mr. SMITH. I believe so. I certainly hope so. I think that being able to assure people that should they come forward, they will have these treatments accessible is a vital part of being able to encourage them to do so. There continues to be substantial concern, I think justified concern, over discrimination based on HIV positivity, so there are some good reasons for you not to come forward and be tested if you think you may be positive.

The overwhelming reason for you to come forward and be tested is, I think now, the availability of effective early medical intervention, but if such intervention is not actually going to be available to you, then I think the encouragement for you to come forward will fall on deaf ears.

Mr. WAXMAN. Do you think this would also be true of drug-abusers, people with very self-destructive kinds of behavior? Will they respond?

Mr. SMITH. I hope so. I think they are likely to respond, perhaps not in as great a number as we would like, but I think the only way that we can in good conscience and effectively urge people to come forward is by being able to tell people that we have a therapy available for them, should they come forward.

Mr. WAXMAN. Dr. Kelen, if someone comes into an emergency room and that person is determined to be immune-compromised, do you dispense prescription drugs like aerosol pentamidine or AZT?

Mr. KELEN. In our particular practice, we generally don't. We have a very strong integrated service because of the kind of commitment the hospital has decided to give for these patients, so we have a very close working relationship with Dr. Smith's group and we prefer not to prescribe things directly.

Mr. WAXMAN. You refer them on?

Mr. KELEN. We refer them on because we can't follow them appropriately and we prefer to get them into a system that will.

Mr. WAXMAN. Thank you.

Mr. KELEN. If I may make one comment regarding intravenous drug users, a surprising number do go out and get themselves self-tested. We see that from the emergency department. So many are asymptomatic, yet they tell us, "Well, I went out to some anonymous clinic or the Red Cross to get myself tested." So it is surprising that they have that motivation to find out whether they are

positive or not, but either don't know or are unfamiliar with the system that is available for them.

Mr. WAXMAN. You think, therefore, that if we—if they knew to come in and get tested and get access to care, the more they are to do it?

Mr. KELEN. I think they are. I mean, they already know—if the emergency department is so readily accessible for them that they use it for all sorts of care, I think if they knew that another source was just as accessible, or something similarly accessible that sort of went hand-in-hand with their behavior, I think they would definitely make themselves available.

Mr. WAXMAN. I want to move on to my colleagues. We may come back to some of these points if they haven't been discussed or there are any questions.

Mr. Dannemeyer.

Mr. DANNEMEYER. Will we have a second round, Mr. Chairman?

Mr. WAXMAN. We will do the best we can. We do have a long schedule.

Mr. DANNEMEYER. All right.

Dr. Silverman, I think you would probably be more comfortable identified on the political left, on the liberal side, than conservative, wouldn't you?

Mr. SILVERMAN. I am comfortable, very comfortable right now, yes.

Mr. DANNEMEYER. I would like to read to you a comment by David Horowitz, who made a speech last October on the AIDS epidemic. I quote him because he is on the left, or used to be. He was an activist of the 1960's in the Vietnam era.

This is what he said, in part:

If we are suffering from the most devastating epidemic of sexually transmitted disease in our Nation's history that is not unconnected to the doctrines of sexual liberation promoted by progressive activists or the protection of alternative lifestyles, the same activists have promoted to the point of crippling the traditional procedures of our public health system. Over a million Americans have been infected with this silent killer, yet nearly 10 years after the virus started its deadly journey, the AIDS lobby has paralyzed our public health system so effectively that we can't even track its deadly course.

This compassionate liberal solution, which compels us not to test and not to report the progress of an epidemic has resulted in the preventable deaths of tens of thousands of young gay males and a steadily growing menace to the population at large.

I would like to have your comment to that statement.

Mr. SILVERMAN. First of all, I don't know who among us, liberals or—in public health are promoting sexual liberation or wanton sexual activity. I think there has constantly been raised that we are more interested in civil liberties than we are public health. I maintain that they are consonant. I think we haven't been paralyzed. I think we have been doing the appropriate job. I think that if one talks to public health officials nationwide, and I don't believe the man who has written that has any public health background or involvement, you will find that we have been proceeding in a very appropriate way.

As has been stated by Dr. Smith, if you try to coerce people to come in, if you try to have a list of names, you are going to have a problem. Now, we are tracking this disease, I think, quite well. We



are not tracking the infection as well because people have been reluctant to come in because many people on the other side of the aisle are trying to keep antidiscrimination legislation from becoming a reality, which would then make people feel comfortable to come in.

But I think that once we can assure people that they won't lose their jobs, they won't lose their houses, they won't be kept from having access to medical care, they will come forward, be counseled and tested and act appropriately, whether they are drug users, whether they are people who have been involved in sexual activity which has placed them at risk.

Mr. DANNEMEYER. I thank you for that. I have another question that relates to the matter of H.R. 4470, the Medicaid Act and HIV Amendments, would define as a person eligible for Medicaid an HIV carrier.

That represents quite a policy determination. I have some data here that indicates that the cost to the Federal Government for that over the next 5 years—the Federal Government's share would be \$2.53 billion. The States would have a similar amount.

If we establish eligibility for Medicaid for HIV carriers, should we then not face the issue that we must also establish the same eligibility for people with cancer or diabetes or heart disease?

Mr. SILVERMAN. I think those are issues that have to be addressed, but I think we are right now in a situation where we know we can provide treatments that will slow the progression of this disease. We can provide something that will be a cost-saving to the government eventually and I think that not to do so, especially when we are dealing with an infectious disease, would be a mistake.

What we should do with the others, and I think it is very clear, and I appreciate your interest in that, I think the mistake we have made has been constantly having AIDS in competition with other health care issues. I think we have to look at AIDS in the issue of all of our priorities nationally, regardless of whether they are health or otherwise.

Mr. DANNEMEYER. The reason I ask this question, quite candidly, is that there is a perception growing in the Congress among members that the quantity of money that the U.S. Government is spending to control this tragic epidemic of AIDS is out of proportion to the quantity of people in our society that are afflicted with heart disease and cancer, for instance, and there is a bit of resentment growing there, quite candidly.

Mr. SILVERMAN. Sir, you are correct. I have noticed that myself. However, I think we have two factors that make this unique. One is that it is infectious. We can prevent the spread of this. We still don't know quite how to totally prevent the spread of cancer. We know how to prevent the spread of this and with good prevention activities and education activities, we can be somewhat successful.

Mr. DANNEMEYER. Have I made you a convert to reportability for HIV carriers and contact tracing yet?

Mr. SILVERMAN. Let me make something very clear, sir——

Mr. DANNEMEYER. That can be answered——

Mr. SILVERMAN. Wait——

Mr. DANNEMEYER. That can be answered yes or no.

Mr. SILVERMAN. Wait a minute. I will give you a better answer. I was the first health officer in the United States in December 1984 to establish contact tracing in San Francisco.

Mr. DANNEMEYER. It is too bad you didn't shut the bathhouses in the early 1980's, though, Dr. Silverman.

Mr. SILVERMAN. No, not really.

Mr. DANNEMEYER. I think it is a tragedy.

Mr. SILVERMAN. We could debate that. We don't have the time right now.

Mr. WAXMAN. The gentleman's time has expired.

Dr. Rowland.

Mr. ROWLAND. I have no questions, Mr. Chairman.

Mr. WAXMAN. Mr. Nielson.

Mr. NIELSON. Yes, I would like to follow up on the question just asked.

In addition to cancer, heart disease and other things which could be considered a disability—whether they are classified disability or not has nothing to do with whether they can be spread or not. It is just a question of their survivability. Disability means that—the lack of ability to perform normal functions.

What about Hodgkin's disease and leukemia, which are, percentage-wise, much more likely to cause death and much sooner than AIDS? Should they be disability? If I am judged to have Hodgkin's disease or leukemia, shouldn't I be disabled in the same fashion?

Mr. SILVERMAN. I think each one has to be looked at very carefully. This bill deals specifically with AIDS, with an infectious process, which is affecting primarily people in the prime of their life, 90 percent between the ages of 20 and 49. I think we should obviously, as I said before, we shouldn't be in competition with other diseases and we should look at that—

Mr. NIELSON. But you are ducking the issue, Dr. Silverman. You say it is because AIDS can be checked and because we can prevent the spread of it. Disability has to do with whether a man can perform, a man can go about his functions. A guy with leukemia or Hodgkin's disease certainly is probably more disabled, and sooner, than this.

Now, my question is, if we are going to call it disabled for AIDS, shouldn't we call it disabled for all life-threatening diseases?

Mr. SILVERMAN. Well, we don't have the time now to discuss it, but I think that—

Mr. NIELSON. Oh, I think you should.

Mr. SILVERMAN. Well, I will, but I think—you know, one of the things that has been interesting to me, as I travel around Europe, these discussions don't come up because there is a health care system in place in all of these nations that take care of these issues. I think it is criminal in a country such as ours that we have to have special acts, special laws to provide care and not have some system of universal health care coverage and I hope that the AIDS epidemic will focus our attention on that shortcoming.

We are the only Nation, except for South Africa, that is in this position, developed nation. So I think you are right. There are other diseases that certainly need to be—that become disabling and I think that we should not have anyone have to suffer through that without being—have the proper access to health care.



Mr. NIELSON. We also have a definition in the H.R. 4470 which talks about abnormally low immune function in terms of T4 cell concentration in the blood for which medical intervention is required. Is this definition, "abnormally low immune function," subject to change as we get more knowledge?

Mr. SILVERMAN. The numbers may change slight, but I think it has become very clear that starting below 500 T-cells, that there are problems, that there is a greater risk of intercurrent infections and certainly below 200, the need for aerosolized pentamidine becomes very, very important.

Mr. NIELSON. You don't think the basic definition would change?

Mr. SILVERMAN. I don't think so, no.

Mr. NIELSON. Because if it did, we would have Medicaid eligibility subject to the change in the definition as we go along, which would be clearly hard to deal with legislatively.

I would like to ask Dr. Smith a question. You talk about the rate of information—no, I guess it is—sorry, it is not Dr. Smith. It is Dr. Kelen.

You state that the black male emergency room patients have a seropositive rate of 16 percent. What is the comparable rate for white males, black females, white females? Do you have those rates as well?

Mr. KELEN. Yes, I do, but let me qualify. That is young black males between the ages of about 25 and 45.

Mr. NIELSON. Twenty-five to 45.

Mr. KELEN. Yes, so it approaches that for—

Mr. NIELSON. If you use those same age groupings, how would that compare with—

Mr. KELEN. The young black females, it is somewhere in the neighborhood of 6 to 7 percent. For young white males, it is fairly comparable, something in the neighborhood of 4 to 5 percent. For young white females, it is very, very low. We only see a few of them.

Mr. NIELSON. Okay. You say that 38 percent of the asymptomatic HIV-positive individuals already qualify for Medicaid. Do you have any idea how they became qualified for Medicaid? Have you pursued that? Do they become qualified for Medicaid on the basis of disability or on other bases?

Mr. KELEN. I truly don't know.

Mr. NIELSON. Because most of them, as you pointed out, are much younger than the normal age for qualifying for Medicaid.

Mr. KELEN. I can tell you, though, that we do serve a particularly poor population, and so I think many of them simply qualify because they don't have jobs and they don't have particular resources at all and they simply fall under the net.

Mr. NIELSON. I was interested in your comment about the fact that most of the increase in emergency room use for HIV-positive individuals is due to intravenous drug use. That is not the common expectation.

Mr. KELEN. Actually, let me clarify that. What I meant there was that the largest increase is among intravenous drug users. It is true that both among the symptomatic and asymptomatic group, the proportion of intravenous drug users, as time is going on over

the last 3 or 4 years, is steadily increasing compared to, say, the other largest risk group that we have, homosexual, bisexual——

Mr. NIELSON. May I ask one more question, Mr. Chairman?

Mr. WAXMAN. Yes.

Mr. KELEN. I think we interpret that that as that those with sexual risk tend to be much more medically sophisticated and they probably are much better off, and so they have health providers and they have reasonable insurance——

Mr. NIELSON. And they don't go through the emergency room process much?

Mr. KELEN. Well, we do see them, but as you can see, most of them are symptomatic, so they are sicker. So they come when they need to. Intravenous drug users come because that is what is available.

Mr. NIELSON. In view of the fact that you have so many intravenous drug users, and that is increasing, did you have a position on whether we should or should not give—issue free needles under the exchange-needles program?

Mr. KELEN. I have to tell you, I am not really qualified to comment on that. I am not involved either in the political process——

Mr. NIELSON. That is another issue before us and I just wondered if you had some guidance in that issue.

Mr. KELEN. I really, truly don't.

Mr. NIELSON. Thank you, Mr. Chairman.

Mr. WAXMAN. Thank you, Mr. Nielson.

We will have a second round.

Let me start off, Dr. Silverman, I interrupted you. I don't know if you had made the point you wanted to make.

Mr. SILVERMAN. One thing I do want to clarify is the Medicaid program does cover people who are disabled by Hodgkin's, people who are suffering from Hodgkin's. The fact is that HIV, the disability, is episodic. In other words, it is not always disabling and the coverage is limited. Of course, early intervention requires access prior to disability.

What we are trying to do is to prevent that disability. Again, in the sense of prevention, and that has been my field for the last 20 years, it is so much better from a humane point of view and from an economic point of view to prevent the disabling conditions and the acute conditions.

Mr. WAXMAN. We have a unique situation under Medicaid. Medicaid, to be eligible, you have to be poor. That is not the only eligibility. You also have to be disabled or elderly or a mother with children and then children and if you are a male, let's say, or a woman without children, you are not eligible even though you are poor until you become disabled. Then you become eligible for the hospitalization and the expensive parts of the AIDS care.

What our proposal would do is not redefine the disability, but to say you would be eligible upon infection and a compromised T-cell immune system in order only to get the early intervention drugs that would keep you, then, from going on to the more expensive costs in the Medicaid system.

Let me—I did want to make that clarification.

Dr. Silverman or Dr. Smith, the Congressional Budget Office has assumed that expanding Medicaid, as I have just described it, to in-



clude these drugs will require paying for all the current hospital care plus the cost of outpatient drugs.

In other words, they don't see that we save money by providing the early treatments therapy. Do you have any comment on it? Would we save money or are we just going to add another cost?

Mr. SMITH. I think we clearly save money. What is not so clear is how long we will save money for. Let's say, aerosolized pentamidine. There is no question that giving people pentamidine or any one of a number of other prophylactic regimens will prevent 70, 75, or 80 percent of those people in the course of 1 year to 18 months from getting pneumocystis. We don't know that it will indefinitely prevent them. It may be that they will get it 3 years from now, 4 years from now, 5 years from now, but it is clear that they won't get it in the next year, the next year and a half.

A lot of what we do in this disease is buy time. What we do is try to keep people from getting sick today so that tomorrow we have something else to offer them. There is no question that if the people that we are seeing who are spending \$14,000 per hospitalization for pneumocystis now had been getting prophylaxis over the course of the last year, a substantial percentage of them would not be clinically ill now.

So there is no question that we will save money. How long we will save it or what horizon, I think we still have yet to find out.

Mr. WAXMAN. Do we know whether there is a reduced hospital cost to treat a patient who had early intervention drugs, let's say aerosol pentamidine, when pneumonia later hits?

Mr. SMITH. We don't know that, no, sir.

Mr. WAXMAN. Just don't know.

Mr. SILVERMAN. Mr. Waxman, Mr. Chairman, I think—the Federal Government has come out very squarely—Dr. Mason has urged testing and the early intervention. Unless we provide the wherewithal to have access to that, it is a very cruel hoax to perpetrate on Americans today.

Again, as I said earlier, I reiterate, it is so tragic that in a Nation of plenty that we have, that we have people that are getting pneumocystis pneumonia, that are becoming disabled with AIDS that could have been prevented.

Mr. WAXMAN. Dr. Kelen, in the emergency room, from your experience, if patients had access to testing and counseling, diagnostics, early intervention drugs, if they had someplace else to go, do you think more of them would go there as opposed to emergency rooms in hospitals?

Mr. KELEN. I think they would. This is based on a different type of experience that we have. At one time, we saw a tremendous number of patients with very trivial illnesses and we developed a clinic system offsite, only about a mile away, but definitely offsite, that we were willing to bus people to, where they could be seen for things that are less emergent. This has been extremely successful.

Although I don't have the numbers, I think we are relatively successful in getting people into Dr. Smith's clinic who are willing to go. I think that overall we would be quite successful in getting people to go the appropriate clinics if we could educate them appropriately that they are available.

Mr. WAXMAN. First of all, if they were available and we could educate people about their availability, more would come. What if there were clinics and people who showed up at these clinics to be tested knew their names were going to be on some list, that they may face discrimination because of the HIV infection, that they wouldn't get any early intervention drugs, all they would get is tested, do you think that they would be more likely or less likely to come into a testing clinic under those circumstances?

Mr. KELEN. I think it depends on the risk group. In all honesty, I think drug users care a tremendous amount whether they are known or not or whether they are on anybody's list. I think all the other risk groups would be scared away from coming forward. I think we would drive the disease underground.

Mr. WAXMAN. Even for the drug abusers, you indicated a lot of them come in someplace or other to get tested, so they are curious enough to know. Do you think they would show up at any testing place where they thought they were going to face sanctions—

Mr. KELEN. I think for the most part they go to an anonymous clinics, although I don't have the data to prove that. I think many drug users, we should point out, do, in fact, have jobs and do, in fact, pay taxes, so not all of them are impecunious. Those that can suffer consequences, I don't think would come forward.

Mr. WAXMAN. Thank you very much.

Mr. Dannemeyer.

Mr. DANNEMEYER. Thank you.

I would like to ask our two physicians on the panel, or at least two of the three, Dr. Kelen and Dr. Smith—Dr. Smith, what State are you licensed to practice medicine in?

Mr. SMITH. California, Pennsylvania and Maryland.

Mr. DANNEMEYER. Dr. Kelen, I think you are from Maryland, aren't you?

Mr. KELEN. I am licensed in Maryland and the Province of Ontario in Canada.

Mr. DANNEMEYER. I see.

Then I would like to ask each of you the questions—in those States where you are licensed to practice medicine, is it mandated that physicians, when they encounter persons with communicable disease report the communicable disease to public health authorities?

Mr. SMITH. Sure.

Mr. DANNEMEYER. Are you familiar generally with those lists of the diseases that are on the reportability list?

Mr. SMITH. Yes.

Mr. DANNEMEYER. Dr. Kelen?

Mr. KELEN. There definitely exists a list and—

Mr. DANNEMEYER. Roughly how many are in the States?

Mr. SMITH. I don't know.

Mr. KELEN. Do you mean—

Mr. SMITH. We rarely see anthrax, but I am sure it is on the list.

Mr. KELEN. There are about 25 to 30 or so.

Mr. DANNEMEYER. There is a handful of venereal diseases on the list of mandatory reportability in the States where you are practiced—licensed to practice medicine, right? And those venereal dis-

eases for which reportability is mandatory are curable, is that right?

Mr. SMITH. I suppose so.

Mr. KELEN. For the most part, I think that—

Mr. DANNEMEYER. So my question—and this bothers the American public extensively—if we mandate the reportability when physicians encounter patients with curable venereal diseases, how come we don't follow the same standard when a physician encounters a patient with a noncurable venereal disease? Why do we do that?

Mr. SMITH. I think you are asking the wrong person, Congressman. I am not—

Mr. DANNEMEYER. Wait a minute. You are a physician licensed to practice medicine in a State in this country.

Mr. SMITH. That is right.

Mr. DANNEMEYER. And it is appropriate, sir, for you to be asked that question because, as I indicated in my earlier comments, we lay men and women in America depend on you in the medical profession for leadership, both in private medicine and in public health, as to how our society should be dealing and controlling communicable disease.

Mr. SMITH. Yes.

Mr. DANNEMEYER. Now, if you have an answer to that paradox, I would like to hear you say it.

Mr. SMITH. Well, what I was beginning to say was that I am a clinician. I am the one who is mandated by public health authorities to so report various diseases. I don't set that policy; I follow it.

I think that in various States, different public health officials have worked out strategies that they feel are appropriate to their State, to the time and place for which diseases are reportable, sexually transmitted diseases and others. I know there is a lot of debate about this. I think there are some very—

Mr. DANNEMEYER. Do you believe, for instance, that we—our society should mandate reportability for HIV carriers in confidence to public health and conduct contact tracing?

Mr. SMITH. That is two questions. I believe that tracing of partners, sexual partners, and drug-using partners of people with HIV infection will often be productive and I think that local and State—

Mr. DANNEMEYER. How about reportability?

Mr. SMITH. I think reportability is something that ought to be decided based on local and State conditions. I think different States have adopted different strategies towards that and I think that is entirely appropriate.

Mr. DANNEMEYER. Would you recommend that be done in your State? Reportability?

Mr. SMITH. No, not right now, no.

Mr. DANNEMEYER. You would be opposed to that?

Mr. SMITH. My State has regulations that require reporting of symptomatic HIV disease.

Mr. DANNEMEYER. Which State is that?

Mr. SMITH. Maryland.

Mr. DANNEMEYER. Okay.



Mr. SMITH. But as I said, Congressman, I am not sure that I am the most qualified person to recommend public health procedures to the public health authorities. I can give them the benefit of my own clinical experience, but I am trying to learn to stay within the areas of my expertise.

Mr. DANNEMEYER. How about you, Dr. Kelen, on that question? Do you think we should mandate reportability for HIV carriers and conduct contact tracing?

Mr. KELEN. My view is not too dissimilar to Dr. Smith in that we follow the laws of the land for the States wherever we practice. We are—the two of us in particular—are not at the leadership level of the public health situation. There are many experts who know this kind of information much better than we and they set the standards and we simply follow them.

Mr. DANNEMEYER. Now let's put it in perspective. The voice of organized medicine in America, the American Medical Association, has said that every State in the Union should have in place a law mandating reportability for HIV carriers and contact tracing.

Do you support the opinion of the voice of organized medicine in America, the AMA?

Mr. WAXMAN. Let me just interject. The AMA is going to testify later and I don't think that that characterization is complete and accurate.

Mr. KELEN. Let me put it this way, in principle, I would be for the reporting of any communicable disease, particularly because of the public health threat. However, the one difference between HIV and all the other diseases on the list is there are major consequences to being identified with this infection.

Mr. DANNEMEYER. Now wait just a minute. We have mandated the reportability for fully developed AIDS cases from the beginning of the epidemic, haven't we? Every State in the Union? From the early 1980's?

We have mandated the reportability of over 125,000 fully developed AIDS cases in America, haven't we? Isn't that true?

Mr. KELEN. I believe it is.

Mr. DANNEMEYER. Can you name one instance where a public health official to whom a fully developed AIDS case has been reported, where that public health official has breached the confidentiality and improperly revealed the identity of somebody who has fully developed AIDS?

Mr. KELEN. I am not aware of such a situation.

Mr. DANNEMEYER. Can you name one instance?

Mr. SMITH. No.

Mr. DANNEMEYER. The point is, sir, that if the existing system of confidentiality has worked to protect the identity of fully developed AIDS cases, as it should, shouldn't we conclude that the same system of confidentiality will work to protect the identity of HIV carriers?

Mr. KELEN. In theory, it should.

Mr. DANNEMEYER. How about that, Dr. Smith?

Mr. SMITH. Actually, no, not necessarily. The fact of the matter is that once someone is a reported AIDS case, they are sick. They are, therefore, much more likely to be known to be sick by others around them, their coworkers, their family, their employers. There



are a million people out there who are HIV-infected, but who are not sick. They have substantial, and I believe justified concerns about the potential for discrimination against them in their private lives——

Mr. DANNEMEYER. Wait a minute now.

Mr. WAXMAN. The gentleman's time has expired. We will have to let that answer stay.

Mr. Rowland.

Mr. ROWLAND. I want to pursue that line of questioning a little bit further.

The greatest increase in the number of HIV-positive individuals, new HIV-positive individuals, is in the drug-abuse community. Is that true or not?

Mr. SMITH. I don't know that we know that. The greatest increase in the number of reported AIDS cases is in the drug abuse community.

Mr. KELEN. By proportion, not in absolute numbers, I believe. By proportionate increase. Sexual risks are still——

Mr. SILVERMAN. When you look at the number of new AIDS cases, the——

Mr. ROWLAND. I am not talking about new AIDS cases. I am talking about number of people who are newly HIV-positive, not the number of people that have—these people may have been positive for years and years, but what I am asking is the number of people that are newly HIV-positive. In our experience at this point, those mostly are drug related?

Mr. SILVERMAN. It is hard to determine, sir, because it depends where the testing programs have taken place. There are a lot of blinded studies at hospitals, emergency rooms, delivery suites and places like that. There was an attempt to have a nationwide household survey and it was tested, but it has never been put into effect nationwide, so we really don't have those numbers.

But if you look at AIDS cases which reflect earlier infection, it seems that there is a rising number in the drug-using community. In major cities where the gay population has been a significant number, new infections have dropped significantly in the gay population.

Mr. ROWLAND. Would it be your opinion that the largest increase of new HIV-infected individuals is in the drug abuse community?

Mr. SMITH. I think perhaps among them, but I think the other fast-increasing number is among sexual contacts of drug users, or sexual contacts of sexual contacts.

Mr. ROWLAND. Then, indirectly it is related to drug abuse? That is your opinion where that is taking place?

Mr. SMITH. Yes.

Mr. ROWLAND. So what we really are interested in is trying to stop the spread of new HIV-infected individuals?

Mr. SMITH. No, sir. That is part of what we are interested in. Even if we stop the spread of new HIV-infected individuals today, there are a million people who are already infected, who will be sick, and when they get sick, they will come to me. I am here to talk about how we are going to be able to try to take care of them.

I am not trying to belittle the task of prevention, but the task of care is a separate task.

Mr. ROWLAND. While that is your primary concern, taking care of sick individuals, that is—the spread is not really your concern.

Mr. SMITH. Of course it is my concern, but it is not my major function. It is something I am interested in; it is something I try to do my part in, but I spend most of my day trying to take care of people who are already—

Mr. ROWLAND. You are a clinician. Let me ask one of the public health—

Mr. SILVERMAN. I think certainly one of the major things we have to try and do is stop the spread. Prevention, again, is one of the most important and most cost-effective things we can do. So, yes, we want to try and stop the spread of this virus and I think it is something that is doable.

Mr. ROWLAND. What is different about dealing with this virus, as compared to, for example, gonococcus syphilis?

Mr. SILVERMAN. One is that the other is treatable. Two, it doesn't seem to carry the burden of discrimination like this one does, and if I can cite an example for both you and for Mr. Dannemeyer, the State of South Carolina went from anonymous testing to confidential testing and registry. The State of Oregon went from confidential testing to anonymous testing.

In the State of South Carolina, the number of people coming in to be tested went down, the number of positive tests went down. In the State of Oregon, where it went to anonymous testing, the number of people coming in went up and the number of positives went up. The point is, whether it is real or perceived, and you are absolutely correct, there hasn't been a breach in public health at this time, but there certainly has been incredible accounts of discrimination against people, and if you have an individual who is going to live, we hope, 10 or more years from the point of infection, for that person to lose their economic base, to lose their housing, to not have access to certain health care, that is a very heavy burden and one that many people, whether it is really going to happen, and it has, or whether it is perceived it is going to happen—of course, perception sometimes is as important as reality—people will stay away.

We can do partner notification without a registry. We can—if I establish a good relationship with my patient, I can get them, hopefully, to bring their partners in or to agree to have me help them bring their partners in. Partner notification or contact tracing is only—makes only good sense in low-prevalence populations. It makes no sense to do that in the city of San Francisco for gay men because every gay man knows he is potentially at risk.

Mr. ROWLAND. Mr. Chairman, since I passed the first time, may I proceed just a little bit further?

Mr. WAXMAN. By unanimous consent, the gentleman will be recognized for—

Mr. ROWLAND. Two additional minutes.

Mr. WAXMAN [continuing]. Two additional minutes in lieu of that previous round.

Mr. ROWLAND. In your opinion, if this was curable, a curable disease, would it be treated differently from the way that it is now, generally speaking?



Mr. SILVERMAN. I think if it were a curable disease, we wouldn't have any problem with people coming forward because I think they would come forward, and if we can't get away from—I mean—and it sounds like it is not health, but it really is. We can't get away from the issue of discrimination. It keeps people from coming forth.

Our goal is to bring people in, have them counseled, have them tested, change their behavior, get on treatment. If our goal is that, we ought to make every effort possible to make that setting safe and effective for that individual, and if they feel—they perceive that it is unsafe, they won't come forward.

The premarital testing program in Illinois was turned around because people went to Wisconsin to get married or just decided not to get married at all and just to live together. The point is, people are worried about this discrimination. We know it happens. Talk to the people. Talk to Ryan White before he died. Talk to the Ray children. Talk to thousands of others. It is real.

What we have to do is make it such that people will come forward on their own volition into a safe environment and then give forth that information. It is to benefit everyone.

But the other thing is that many of these diseases on the list that these gentlemen work under are casually spread, are easily spread without the knowledge of someone else. If we can educate everyone not to place themselves at risk—this is a disease basically of consenting adults, and if we are not careful, consenting youth, and except for rape, and unborn children coming from infected mothers, you have to place yourself at risk.

Let's put our energy into educating people so they don't do that and then we don't need these names——

Mr. ROWLAND. So if we had a policy that addressed the problem of discrimination, we wouldn't have a problem about contact tracing?

Mr. SILVERMAN. We would have a much lower problem about that, and again, you can't have mandatory contact tracing. That is an oxymoron. I can't force you to divulge to me who your partners are. What it takes is a good relationship, and if we have a good relationship, whether I know your name or not, I can work on notifying your partner and getting your partner in. That is what is important.

Mr. ROWLAND. Thank you, Mr. Chairman.

Mr. SMITH. Mr. Rowland, if I could respond just for 1 second, it seems to me that for many individuals and for policymakers such as yourselves, too, the question of whether to get tested is a balance. There are pros and cons and I, frankly, have been long an advocate for encouraging people to be tested.

But I think that you now are finding lots more people encouraging people at risk to be tested than 2 or 3 years ago, in part because I think discrimination is not as big a problem as it was 2 to 3 years ago. I think we are making progress. Also because there is more effective treatment.

So, if discrimination is one of the cons and if the lack of availability of treatment is also one of the cons, as both of those improve, I think people are more willing to be tested. I think you are seeing lots of organizations, individuals, changing their positions, and yes, I think as we get more and more effective therapy, includ-

ing a "cure," I think we will all, as will many individuals at risk, reconsider this balance in their minds.

So I think it is one of a number of things that people get weighed and I think you are seeing a transition in people's thinking as the therapies get better.

Mr. WEXLER. Congressman, if I can address this question for just a moment, I am not a doctor. My stories are anecdotal. I have become quite a proselytizer for testing. In fact, I have become downright obnoxious about it.

I have encouraged all of my friends and colleagues to become tested and I do that repeatedly if they don't do that. It is often incredibly difficult to get someone to go in for testing because that person is afraid, first, of the results; second of all, of discrimination; third, that his name will end up on some list; fourth, that he will be forced to reveal the names of all the people he has been to bed with for the last 10 years.

If any of those things are prevalent, it is much more difficult to get him to go in to get tested. Each one of those things that you remove, it is easier to get him to go in and get tested. If what we are trying to do is get people to volunteer to be tested so that we can monitor them and treat them, then the way to do that is to assure them, one, of confidentiality; two, that their names will not end up on a list; three, of nondiscrimination. Otherwise, they will not volunteer.

Mr. DANNEMEYER. Mr. Chairman, may I ask the gentleman an additional question?

Mr. WAXMAN. It is Mr. Nielson's time. Maybe he will yield—

Mr. NIELSON. I will yield a minute to Mr. Dannemeyer.

Mr. DANNEMEYER. Mr. Wexler, you are from Los Angeles County, CA, right?

Mr. WEXLER. That is correct.

Mr. DANNEMEYER. Are you familiar with the existing practice in Los Angeles County for how public health deals with contact tracing for curable venereal disease patients?

Mr. WEXLER. No, I am not.

Mr. DANNEMEYER. Let me advise you how that practice currently exists. When a physician in Los Angeles County finds a patient with a curable venereal disease, syphilis or gonorrhea, the doctor is required by law to breach the confidentiality of the doctor/patient relationship and report the patient's name, address and Social Security number to the Los Angeles County Public Health Department and contact tracing takes place.

This is how contact tracing currently takes place. The public health worker calls up the patient and says, "Who were your sexual contacts whereby you acquired this disease?" If the individual says, "Stop bothering me, I am going to call the ACLU", the health worker says very politely, "Sir, if you do not voluntarily surrender your sexual contacts, we will come out and take you into custody."

That is the current practice in Los Angeles County.

Mr. WEXLER. Congressman—

Mr. DANNEMEYER. Most people—let me finish, sir. Most people get the message. They don't push it that far.



Now, we have put up, in our society, with equanimity, with the invasion of our civil liberties, as I have described, so profound is the policy of our public health authorities to prevent, if we can, the transmissibility of curable venereal disease. And for our society to not follow this same practice and apply the same standards in controlling a noncurable venereal disease has prompted a lot of people in this country to really question what has happened to the common sense of the public health officials of America.

Mr. WEXLER. Congressman, you are talking apples and oranges. You are talking about a disease that has shown symptoms where a person has to come in and get treated. I am talking about a disease that is asymptomatic, where testing is voluntary——

Mr. DANNEMEYER. And I am submitting, Mr. Wexler——

Mr. WEXLER [continuing]. And the question—let me finish, sir——

Mr. DANNEMEYER [continuing]. You are concentrating on the status of the infected and ignoring the civil rights of the uninfected.

Mr. WEXLER. I am concentrating on——

Mr. NIELSON. Taking back my time, from what sources does Los Angeles get its funds to treat AIDS? What sources do you have?

Mr. WEXLER. I am sorry, I didn't hear——

Mr. NIELSON. From what sources does the AIDS Project get money?

Mr. WEXLER. AIDS Project gets 70 percent of its money from private sources, mostly from personal donations, some foundation grants, but mostly from personal donations. Thirty percent from government grants.

Mr. NIELSON. Thank you. If we pass H.R. 4470, how many more people could you treat than you do now? How many more people could you take care of if you had more——

Mr. WEXLER. We would hope that there would be enough funds that we could take care of the people that will——

Mr. NIELSON. That is not my question. How many more would you take care of if you have H.R. 4470——

Mr. WEXLER. I don't have that figure, Congressman.

Mr. NIELSON. Would you get it for me?

Mr. WEXLER. Certainly.

Mr. NIELSON. Thank you.

Of the individuals you serve, how many provide information for contact tracing? Any of them?

Mr. WEXLER. We don't get into contact tracing.

Mr. NIELSON. Do some of them offer contact tracing?

Mr. WEXLER. It is not one of our services. We never ask——

Mr. NIELSON. But if someone told you that they were willing to—perfectly willing to let you let their partners know about it, would you follow up?

Mr. WEXLER. Would I call their partners?

Mr. NIELSON. Yes.

Mr. WEXLER. No, I would try to get them to go to the proper State agencies to get that done. I don't have the skill to go and talk——

Mr. NIELSON. In connection with that, you mentioned that we are not supposed to lose sight of the fact that it discriminates against

them if we do require the listing of partners. What about their spouse? Should the spouse know?

Mr. WEXLER. If I were HIV-infected, I would want my spouse to know, and I would hope that I would tell my spouse that I was. But that is——

Mr. NIELSON. The trouble is, if the spouse does not know, it might affect the next generation, as you know. Many children born innocent—like the boy who just died—were innocent of anything on their part. It seems to me like the spouse ought to at least be given that information.

Mr. WEXLER. But if the person who is infected never comes in to get tested in the first place, neither he nor his spouse will ever know.

Mr. NIELSON. I grant that, but if he does come in and it is known it will affect their relationship, their children, everything else, shouldn't the spouse know?

Mr. WEXLER. But if he——

Mr. NIELSON. Just answer yes or no. Should the spouse know?

Mr. WEXLER. Yes.

Mr. NIELSON. Thank you.

You mentioned the soon-to-be infected with HIV. What steps are you trying to do to eliminate or minimize that number?

Mr. WEXLER. We have an education program where we are trying to get people to, first, get tested, and second of all, to learn of safe sex techniques and how the disease is spread and how they can prevent the disease from spreading. We have been quite successful at that.

Mr. NIELSON. Thank you, Mr. Chairman.

Mr. WAXMAN. Thank you, Mr. Nielson.

Gentlemen, thank you very much for your testimony. You have done an excellent job, each of you, and you have been very helpful to us.

The next panel is made up of the following witnesses: The Honorable Joseph Lisa is chairman of the New York City Council Committee on Health; Dr. William Jones is president-elect of the Medical Society of Arkansas; Dr. Jerome Schwartz is representing the Medical Society of New York; and Dr. Barbara Rockett is past president of the Medical Society of Massachusetts.

We are pleased to welcome you to our hearing today. Your prepared statements will be in the record in full. What we would like to ask each of you to do is to limit your oral presentation to no more than 5 minutes and we will have to be quite strict on that 5-minute time constraint.

Mr. Lisa, why don't we start with you.

STATEMENTS OF JOSEPH F. LISA, CHAIRMAN, NEW YORK CITY COUNCIL HEALTH COMMITTEE; WILLIAM N. JONES, PRESIDENT-ELECT, ARKANSAS MEDICAL SOCIETY; JEROME SCHWARTZ, ON BEHALF OF MEDICAL SOCIETY OF THE STATE OF NEW YORK; AND BARBARA A. ROCKETT, PAST PRESIDENT, MASSACHUSETTS MEDICAL SOCIETY

Mr. LISA. Good morning, Chairman Waxman, and members of the committee. I appreciate the opportunity you have afforded me to comment on H.R. 4470, the AIDS Prevention Act of 1990.

Mr. Chairman, as you well know, we worked together in the 1970's to end discrimination against Americans in passing antiblack list boycott legislation, you in the Federal stage and I, of course, in New York. Again, I look forward to working with you for the protection of the public health in times of epidemics.

The purpose, Mr. Chairman, and members of the committee, of the public health legislation is to accomplish two mainstays: One, the care of the sick, and two, the protection of the uninfected. With that mainstay in place, I know that you will understand my comments.

Insofar as section 2602 is concerned, the requirements in respect to an informed consent is concerned, may I respectfully suggest that you seriously consider the tremendous burden that is being placed upon health care providers of our Nation in requiring testing only after obtaining from the individual a statement declaring that the individual has undergone counseling and then having them sign that statement.

This complex and time consuming requirement with no allowance for flexibility on the part of the physician places an unnecessary burden upon an already stressed health care system and may, in time, in my opinion, prove to be a serious impediment in preventing physicians from being able to best diagnose and best treat a patient. You may wish—and I say this as a lawyer legislator of 20 years' experience—to do just the reverse.

I encourage you to seriously consider making HIV testing a routine examination with all other routine requests and require a written statement only if and when the patient declines to be tested. The right not to be tested must be respected. This procedure would protect all parties concerned by providing for the mechanism for refusal to be tested in writing.

Insofar as section 2603 is concerned concerning counseling, I do not pretend to know the fiscal status in all 50 States. However, in the Northeast, we are experiencing serious fiscal problems.

In my State, Mr. Chairman, the State of New York, we are facing an estimated \$1.5 billion budget gap, which is presently being addressed to contemplated cuts in services, layoffs and new taxes. Counseling, as described in H.R. 4470, may prove to be a high-priced item which could be significantly reduced in cost by allowing physicians to exercise discretion and provide appropriate counseling, both pre- as well as post-, on a case-by-case basis. This conforms to the present practice followed by the health care community in almost all medical situations.

Insofar as section 2605 is concerned, I am very, very pleased with this provision in encouraging and offering preventive health care



services. I support the concepts contained in section 2605 of the bill.

Might I point out that we might want to extend it to HIV antibody testing to be routinely offered to marital applicants and to pregnant women. I need point no further than to the New York State experience.

Three years ago, we virtually eliminated congenital syphilis in New York. We, as some other States, then abolished blood testing for marital applicants, which was the mainstay for protecting infants from this often fatal disease for the past 50 years. We are presently faced with an explosion of congenital syphilis in massive epidemic proportions.

We all recognize that this alarming effect may also be accompanied by HIV infections from the same infected population group. I suggest you also consider including court-ordered testing for certain specific categories of persons: victims of rapes and sodomies, children who have been subjected to fully consummated sex offenses, health care providers, peace officers, fire fighters, EMTs, court officers and correction officers.

Insofar as section 2607 is concerned, reporting and contact tracing—let me tell you, New York, last year, passed article 27-F of the New York State Public Health law, the strongest HIV confidentiality statute in the Nation. It was bottomed on a legislative intent that maximum confidentiality will encourage people to come in to be tested. Do you know what happened? Practically the same number of people came in in the one year that article 27-F has been in effect to be tested as in previous years.

Don't we understand that the HIV epidemic, as compared to the AIDS epidemic—and they are two separate epidemics—the HIV epidemic has always been underground and still remains underground in New York, in spite of the HIV confidentiality statute that we passed.

We have an estimated 200,000 to 400,000 HIV infections in New York and less than 10 percent of that population has been tested. That means that 90 percent of those that are HIV-infected and infective have not been tested in New York. I warn you not to make the mistake we have made in New York.

Mr. Chairman, in view of the time provisions, might I commend you to read the last page and a half unless I might be permitted on question and answer to talk about my comments as contained in the written statement.

Mr. WAXMAN. The whole statement is going to be in the record and it may well come up during the questions and answers.

Mr. LISA. Thank you.

[The prepared statement and attachment of Mr. Lisa follow:]

STATEMENT OF JOSEPH F. LISA, CHAIRMAN, NEW YORK CITY COUNCIL HEALTH COMMITTEE

Good morning, Chairman Waxman, and members of the committee, I appreciate the opportunity you have afforded me to comment on H.R. 4470, the Aids Prevention Act of 1990.

Insofar as section 2602, requirements with respect to confidentiality and informed consent is concerned, may I respectfully suggest that you seriously consider the tremendous burden you are placing upon the health care providers of our Nation in requiring testing: "Only after obtaining from the individual a statement, declaring



that the individual has undergone the counseling described in section 2603(a) and that the decision of the individual with respect to undergoing such testing is voluntarily made."

This complex and time-consuming requirement with no allowance for flexibility on the part of the physician places an unnecessary burden upon an already stressed health care system and may in time prove to be a serious impediment in preventing a physician from being able to best diagnosis and best treat the patient.

You may wish to consider making the HIV antibody test part of the "routine" examination as with all other "routine" tests and require a written statement, only if and when, the patient declines to be tested.

The right not to be tested must be respected and this procedure would protect all parties concerned by providing for the mechanism for "refusal" to be tested to be required in writing.

Insofar as section 2603, requirement of provision of certain counseling services is concerned, I do not pretend to know the fiscal status of all 50 States; however, in the Northeast, we are experiencing serious fiscal problems.

In my State, the State of New York, we are facing an estimated "\$1.5 billion budget gap which is presently being addressed through contemplated cuts in services, layoffs, and new taxes.

Counseling, as described in H.R. 4470 may prove to be a high price item; which, could be significantly reduced in cost by allowing physicians to exercise discretion and provide appropriate counseling, both pre as well as post on a case-by-case basis.

This conforms to the present practice followed by the health care community in almost all medical situations.

Insofar as section 2605 offering and encouraging preventive health services is concerned, I support the concepts presently contained in section 2605 of the bill, requiring the offering and encouraging preventive health service in STD, drug abuse, family planning, and TB clinics; however, I would suggest you seriously consider adding the requirement that the HIV-antibody test be routinely offered to marital applicants and to pregnant women. I need point no further than to the New York experience. . . .

Three years ago, we virtually eliminated congenital syphilis in New York.

We, as some other States, abolished blood testing for marital applicants, which was the mainstay for protecting infants from this often-fatal disease of the past 50 years.

We are presently faced with an explosion of congenital syphilis in massive epidemic proportions.

We all recognize that this alarming fact may also be accompanied by HIV-infection within the same infected population group.

I also suggest you consider including court-ordered testing for certain specific categories of persons; for example, victims of rape, sodomy, and child sex offenses, health care providers, peace officers, firefighters, EMT's, and court and correction officers, as contemplated in my resolution No. 142 introduced in the city council of the city of New York (a copy annexed hereto).

Insofar as section 2607 requiring reporting and contact tracing with respect to cases of HIV-infection is concerned, may I point out that the current HIV epidemic, which will be the AIDS epidemic of the 1990's, is a new epidemic of ever more increasing cases of "families."

The future cases of AIDS will result from HIV infections in minority, poor, women, babies and adolescents.

And, because of these facts, we must begin to use contact tracing and partner notification as part of our public health approach to the new epidemic.

We cannot wait until the silent and invisible HIV infections become clinically symptomatic for then it may be too late for too many.

The spread of heterosexually transmitted HIV-infections in the above-mentioned population groups is a direct result of the lengthy incubation period accompanied by insufficient utilization of HIV antibody tests.

In New York City, where we have an estimated 200,000 to 400,000 cases of HIV-infections, less than 10 percent of those infected have been tested.

The remaining 90 percent do not know that they are infected and infective.

I warn you not to make the mistake we may have made in New York,

Our new HIV-confidentiality law article 27-F of the NYS public health law was enacted on a legislative finding that maximum confidentiality will encourage testing.

In the first year of its enactment we witness no appreciable increase in HIV-testing than in previous years.

We in New York have the strongest confidentiality statute in the Nation and the HIV epidemic continues to remain underground.

This unfortunate fact is further compounded when we recognize that the New York statute changes what was the "duty" of the physician to warn spouses and other contacts of sexually transmitted infections to a "permissive" act.

In New York, a physician may warn a contact only if he or she has reason to believe the patient will not inform their partners.

If mistaken in this critical judgment call the physician can be held liable in a civil suit and prosecuted for a misdemeanor crime.

As a result of these "chilling" provisions, it is no wonder that in 1989 in New York City, the major epicenter of the AIDS epidemic in the western hemisphere, not one single private physician reported one case of HIV-infection to the New York City Department of Health for contact tracing and partner notification.

This failure to protect the public health is further dramatized by the fact that during that period private physicians submitted more than 50,000 specimens, of which 11,000 were HIV-positive.

Finally, I have introduced and passed resolution No. 278 supporting the Kennedy-Hatch bill (S. 2240) which would provide for financial relief to those metropolitan areas hardest hit by the AIDS public health disaster; and, I fear that the conditions contained in H.R. 4470 may prevent these funds from being distributed to those areas unless there is a strict compliance with the terms and conditions of this legislation as presently drafted.

Thank you for the opportunity to comment on this most vital subject. Should you have any questions, I would be delighted to answer them.

#### RESOLUTION No. 142—JANUARY 23, 1990

Resolution calling upon the State Legislature to amend Article 27-F of the Public Health Law to allow individuals in the following categories who have had direct skin or mucous membrane contact with the blood or other bodily fluids of another individual, to obtain a court order requiring the latter individual to be tested for HIV infection and other communicable diseases, if the court determines there is reason to believe that such contact may have occurred: victims of rape, sodomy, child sex offenses and other sex crimes; health care providers, employees of a health care facility, EMTs and firefighters while in the performance of their duties, and police officers and peace officers, including uniformed court officers and correction officers, when assisting an individual in the course of their duties or when involved with an individual interfering with their duties, who has been criminally charged.

By Council Member Lisa.

Whereas, The New York State Division of Substance Abuse Services estimates that there are between 200,000 and 230,000 intravenous drug users ["IVDU's"] in New York State, and that 55 percent to 60 percent of them are infected with the human immunodeficiency virus ["HIV"], indicating that there may be as many as 150,000 HIV-infected IVDUs presently living in New York City; and

Whereas, The New York State Department of Correctional Services estimates that 70 percent of all felons convicted in New York State in 1987 were using "hard" drugs at the time they committed their crimes; and

Whereas, In 1988 there were 37,093 drug-related arrests made in the City of New York; and

Whereas, In 1988 there were 3,412 complaints of forcible rape, 565 complaints of sodomy and 1,054 complaints of sexual abuse reported to the New York City Police Department; and

Whereas, In the same year there were 4,249 complaints concerning incidents in which police officers were assaulted in the City; and

Whereas, The U.S. Centers for Disease Control states that HIV can be transmitted through intimate sexual contact, as well as by exposure of the eyes, mucous membrane tissue or broken skin to the blood of an HIV-infected individual; and

Whereas, Section 2781 of the New York State Public Health Law prohibits involuntary HIV testing, and further prohibits such testing without the written consent of the party being tested, except under very limited circumstances; and

Whereas, As the number of persons infected with HIV increases, the probability of infection by the virus also increases for those who work in occupations that may involve the exchange of blood or other bodily fluids, such as health care providers employees of a health care facility, EMTs, and firefighters and for police officers and peace officers, who are often bitten, scratched, spit upon, or otherwise involved



in a potential exchange of blood or other bodily fluids in the course of their duties; and

Whereas, The United States Food and Drug Administration and Dr. Louis Sullivan, Secretary of the United States Department of Health and Human Services, now recommend early diagnosis of HIV infection, so that treatment with medication, such as Azidothymidine, can be prescribed immediately to attempt to limit, and perhaps stem, the spread of the HIV infection; now, therefore, be it

Resolved, That The Council of the City of New York calls upon the State Legislature to amend Article 27-F of the Public Health Law to allow individuals in the following categories who have had direct skin or mucous membrane contact with the blood or other bodily fluids of another individual, to obtain a court order requiring the latter individual to be tested for HIV infection and other communicable diseases, if the court determines there is reason to believe that such contact may have occurred: victims of rape, sodomy, child sex offenses and other sex crimes; health care providers, employees of a health care facility, EMTs and firefighters while in the performance of their duties, and police officers and peace officers, including uniformed court officers and correction officers, when assisting an individual in the course of their duties or when involved with an individual interfering with their duties, who has been criminally charged.

Referred to the Committee on Health.

#### RESOLUTION No. 278—MARCH 8, 1990

Resolution commending Senators Edward M. Kennedy and Orrin G. Hatch for introducing S. 2240, a bill which would provide grants to improve the quality and availability of care for individuals and families with AIDS and HIV disease, and commending Senators Daniel P. Moynihan and Alfonse M. D'Amato for cosponsoring this bill and urging the Congress to immediately enact this legislation.

By Council Member Lisa; also Council Members Castaneira, Colon, DiBrienza, Dryfoos, Eisland, Eldridge, Fields, Foster, Geroges, Greitzer, Harrison, Horwitz, Leffler, Maloney, McCaffrey, Michels, O'Donovan, Pinkett, Robles, Ward, Williams and Wooten.

Whereas, The New York City Department of Health reports that as of January 12, 1990, the City has recorded 24,626 cases of acquired immunodeficiency syndrome [AIDS], as defined by the Centers for Disease Control [CDC], and 15,621 deaths from the disease; and

Whereas, The New York State Department of Health believes that there are currently between 180,000 to 360,000 individuals in the City infected with the human immunodeficiency virus [HIV]; and

Whereas, CDC estimates that the incubation period of HIV from the time of infection to symptomatic diagnosis is ten years and the New York City AIDS Task Force projects that the City's new cases of symptomatically ill HIV-infected persons as well as persons with AIDS will total as many as 10,739 in 1990 and will continue to increase so that in 1993 there will be as many as 16,001 new cases; and

Whereas, The AIDS Task Force further projects that the cost, stated in 1989 dollars, of providing only seven important HIV-related services in the City, such as acute inpatient care, skilled nursing facility care and outpatient physician visits, will be \$1.176 billion in 1990 and will increase to \$1.844 billion in 1993; and

Whereas, In its report, "The State of New York City's Municipal Hospital System" for Fiscal Year 1989, the City Hospital Visiting Committee notes that the health care system "is already almost overwhelmed by substance abuse and AIDS patients and the stress they place on acute care, psychiatric services, women's health and neonatal services, and long-term care"; and

Whereas, Dr. Stephen C. Joseph, former New York City Commissioner of Health, has stated that "those most affected by the 'new' epidemic of AIDS are blacks, hispanics, women, children and the poor and minority residents of New York City who may not even know they are at risk of infection" and Health and Hospitals Corporation has found that as the epidemic shifts into such populations, the intense pressures on its system will compromise patient access and the quality of care; and

Whereas, It is critical that New York City maintain a health care system which provides HIV-related services necessary to respond to the medical emergency resulting from the AIDS epidemic; and

Whereas, According to CDC, New York City, at the end of 1989, had twenty-one percent of the AIDS cases in the United States; and

Whereas, The federal government provides emergency funds where natural disasters devastate specific geographical areas in order to ensure the health and safety of its citizens; and

Whereas, Senators Edward M. Kennedy and Orrin G. Hatch have this week introduced a bill, S. 2240, entitled the Comprehensive AIDS Resources Emergency [CARE] Act of 1990, which would provide grants to improve the quality and availability of care for individuals and families with AIDS and HIV disease, providing emergency relief to those metropolitan areas hardest hit by the AIDS public health disaster, as well as direct grants to states to develop more effective and cost efficient systems for the delivery of essential health and support services; and

Whereas, The bill would also require the Secretary of Health and Human Services to commission independent research by experts in health services delivery and financing; now, therefore, be it

Resolved, That the Council of the City of New York commends Senators Edward M. Kennedy and Orrin G. Hatch for introducing S. 2240, a bill which would provide grants to improve the quality and availability of care for individuals and families with AIDS and HIV disease, and commends Senators Daniel P. Moynihan and Alfonse M. D'Amato for cosponsoring this bill and urges the Congress to immediately enact this legislation.

Adopted.

Mr. WAXMAN. Mr. Jones.

#### STATEMENT OF WILLIAM N. JONES

Mr. JONES. Chairman Waxman, members of the committee, I am Dr. William N. Jones, of Little Rock, AR. I am a dermatologist in private practice. I am president-elect of the Arkansas Medical Society, chairman of the Committee on AIDS of the Arkansas Medical Society, a member of the Governor's Advisory Committee on AIDS and a clinical professor of dermatology at the University of Arkansas' School of Medicine.

Although I am a member of the American Medical Association, I am not here today as an AMA spokesman.

The principal reason I am here today is to implore you to include in any legislation on the Acquired Immunodeficiency Syndrome the requirement that HIV seropositive persons be reported to the Departments of Health of the 50 States for the purpose of contact tracing and partner notification.

I am pleased to tell you that in December 1989, this became the recommendation of the American Medical Association. It is past time for our government to take this step to help control the spread of the HIV epidemic.

For far too long, we have failed to apply the same public health measures to contain the HIV epidemic as are taken to control the spread of other communicable and sexually transmissible diseases. AIDS has resulted in more than 76,000 deaths in this country. Reportability and contact tracing are new strategies in the control of sexually transmissible diseases. Reportability and contact tracing make it possible for the infected person to be counseled on all aspects of the infection and the determination of his or her sexual and drug contacts so they may be interviewed, counseled and offered testing.

For more than 40 years, this process has been an historically proven technique for the control of sexually transmissible diseases and, in large measure, is responsible for the control of syphilis and gonorrhea.

As of July 1989, 28 States required the reporting of persons infected with Human Immunodeficiency virus. Colorado was the first



State with such a regulation. Early experience in Colorado indicated that of the first 260 contacts interviewed, counseled and tested, 42 were seropositive for HIV, an infection rate of 16.2 percent.

We have been reporting in contact tracing in the State of Arkansas since June 1988. Our contact infection rate is 15.7 percent. It is apparent that those persons that were previously unaware of their infection and the potential for spreading the infection to their sexual and drug contacts—it is apparent that those persons were potentially infectious to others.

Those contacts that tested negative were counseled and educated about their risk behavior and were offered repeat testing to cover the window, the interval between infection and becoming seropositive. Early arguments against reportability and contact tracing were not well-founded and certainly are without merit now. The rights of an individual to privacy and confidentiality are protected in any sexually transmissible disease program. Concerns about the occasional breach of privacy and confidentiality of the individual have to be second considerations to the right of the public to be protected from this fatal viral epidemic.

Concern for the previously uninformed contact has been neglected. Some said there is no treatment; therefore, there is nothing to offer newly found seropositive persons. AZT has been unequivocally shown to lengthen the interval between the onset of infection and the development of symptomatic disease.

It is important for us to remember that HIV infection is a continuum of disease leading to death. The infected person is infectious to others from very early in his or her infection. To require reportability at the end stage of this process for statistical purposes and not require the reporting of infection is incomplete policy and not in the best interests of the health and welfare of the citizens of the United States.

The longer we delay in putting this process into action, the greater the tragedy and loss of lives that could have been saved by these measures.

Mr. Chairman, I would like to add to my written testimony. I have been sitting here since the beginning of this session today and speaker after speaker has talked about the strain on the purse strings of our cities, our States and our Federal Government, and have expressed compassion for the ill and the dying. I think that those points just reinforce the necessity for reporting and contact tracing earlier. They speak of intervention, but intervention makes more sense early. Find the person who unknowingly is being exposed to the disease.

That is the end of my remarks. Thank you, Mr. Chairman.

Mr. ROWLAND [presiding]. Thank you, Dr. Jones.

Dr. Schwartz.

Mr. SCHWARTZ. In the absence of Mr. Waxman, I will just address the distinguished—

Mr. ROWLAND. I am chairing right now and I give you permission to go ahead.

## STATEMENT OF JEROME SCHWARTZ

Mr. SCHWARTZ. Dr. Rowland, I am Dr. Jerome Schwartz, a practicing obstetrician and gynecologist on Long Island in New York State.

A year ago, as president of the New York State Society of Obstetricians and Gynecologists, I appeared here in Washington before a similar health committee in support of the bill, H.R. 3102, introduced by Congressman Dannemeyer. At that time, our organization, in concert with two other New York State organizations, instituted the suit against Dr. David Axelrod, the New York State Commissioner of Health, to force him to declare AIDS a communicable and sexually transmitted disease.

If AIDS were so declared, it would then become an appropriate subject for the Public Health Council of New York, which would have the power to deal with any matter affecting the health, public health or security of life of all New Yorkers. We lost the first round, but the matter is still in the courts.

At the present time, our country is faced with a new disease of epidemic proportions. Prior to 1981, there were only five reported cases of AIDS. To date, we have 125,000 reported cases, of which 70,000 have died. There are 1,000 new cases of HIV seropositive patients reported daily in the United States, the rate doubling in numbers every 13 to 15 months.

The Rand Corporation projections are that in the year 2000, there will be between 5 to 14 million cases of AIDS in the United States if there is no amelioration of the rate of infection. If the general population were to be tested today, at least 1.5 million people would test HIV-positive.

The significance of these grim projections is clear. The impact of the AIDS epidemic on our citizens, our hospitals and our country will exceed any public health crisis faced in modern times. Ten percent of all hospital costs are AIDS-related, approximately \$1 million per day in the United States.

The estimated cost of caring for these patients over the next 4 years will be approximately \$40 billion. I might include, when I first wrote this up, I didn't know how to write \$40 billion, so we had to write it out instead of just putting zeroes after the \$40.

In order to stem the marked increase of numbers of HIV seropositive and AIDS patients, we firmly believe in HIV antibody testing in every public and private clinical facility for sexually transmitted diseases, IV drug users, family planning, tuberculosis, health emergency rooms, hospital outpatient departments, private physicians' offices and various public funded test sites.

Mandatory HIV testing should be reserved for all prisoners and contact prison personnel. All testing, either mandatory or voluntary, must be accompanied by confidential counseling.

Written consent must not be mandated inasmuch as there are many extenuating circumstances where a written consent was not and cannot be obtained, unconscious admissions to emergency rooms and recalcitrant drug addicts.

Seventy-seven percent of pregnant women who are seropositive will transmit the virus to the newborn. In the 5 boroughs of New York, 101 neonates tested positive for HIV infection. In the Bronx,



1 out of every 44 neonates test positive for the HIV virus. Newark, NJ has the highest rate in the United States, where 1 out of every 20 neonates test positive for the HIV virus.

Yet, with these crushing numbers, there is no mandate to test pregnant women for the virus.

On the other hand, in New York State, where there has been an increase in congenital syphilis in the newborn from 41 cases in 1984 to 377 cases in 1988, mandatory testing of all newborns for syphilis has been reinstituted. We believe that all pregnant women must be tested for HIV virus when they are in a hospital setting prior to delivery.

Our organization supports the concept of confidential reporting of HIV results to the appropriate public health officials and the implementation of partner notification programs. This is an absolute necessity so that those partners who are seropositive may have the opportunity to avail themselves of present treatment and to change their behavior to prevent the transmission of the virus to others. Those partners who are seronegative after appropriate counselling and education may change their pattern of behavior before they too become seropositive. May I just continue for about another minute, another 30 seconds, sir.

Mr. WAXMAN. Just conclude your remarks.

Mr. SCHWARTZ. At the present time, we have a plague upon our land. If we now institute a vigorous and comprehensive national prevention and treatment program, we may be able to slow down this epidemic and save large numbers of lives and substantially reduce the enormous burdens and costs of this epidemic in years to come.

I want to thank you for the privilege of letting me come to address you.

Mr. WAXMAN. Thank you very much, Dr. Schwartz.

Ms. Rockett, I am going to interrupt you for a minute before we get started with your testimony.

Our colleague, Congressman Frank Guarini, who was to testify earlier, is now here. He has been tied up on the Budget Committee deliberations and I wanted to ask if he would come forward and present his testimony to us. I know he is going to have to leave very, very shortly. Then we will come back to you.

#### STATEMENT OF HON. FRANK GUARINI, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF NEW JERSEY

Mr. GUARINI. Thank you very much, Mr. Chairman. As always, you are very gracious and I appreciate being able to have my remarks made at this time out of order. I understand that Senator Lautenberg was here this morning and had testified concerning the amendment that I am also very, very deeply interested in, and the budget hearings are not by any way unrelated to what we are doing here today, so I feel as though I can wear a double hat right now.

I want to commend you, and I have very great respect for the work that you have been doing with regard to bringing to the national attention and passing legislation dealing with our urgent

health problems, and particularly in reference to the scourge that we have concerning AIDS in our country today.

I want to thank you for introducing this bill, H.R. 4470, as I believe it will be an important step along the way to beat the emergency funding that is necessary for the epidemic that we have in our country.

I come from Hudson County, a poor, workingman's district. The population of the unemployment is double the unemployment rate of the rest of the State of New Jersey. It lies just opposite Manhattan. As you know, in your bill, of the 13 centers, New York City is one of the largest areas that is going to receive the aid from title III. I believe it is something like \$50-some-odd million, \$59.8 million of the \$150 million. So you see, New York City is tremendously infested with this crisis.

On the other side of us, there is Newark, NJ, which is one of the 13, which has one of the more egregious problems in our country.

Now, we are geographically located directly in the center of these two areas which is the PMSA, I believe they call it, areas that are the criteria. We are actually the epicenter. We have a population of 540,000 people. We have 1,428 AIDS cases that are actually documented today. We had a 78 percent increase in the epidemic rise between 1988 and 1989. We know that it is growing incrementally. We understand that 1 out of every 100 babies are documented to be born with AIDS today in Jersey City. It is the fourth per capita highest in the Nation, our AIDS crisis that we have.

The health authorities believe that the number is much greater than 1 in 100 of the babies that are born and the AIDS cases that we have that we are dealing with in our community. We have many people, good civic leaders, doctors, hospitals that are tuned to work in trying to stem this tide of AIDS that we have.

We have pilot projects that are running out of money. An AZT pilot project by NIH is presently under way in the Jersey Medical Center. We also have a project for infant children who are born with AIDS, that is running out of money.

The Medical Center, which is just one of the hospitals in the area, is running a \$2 million deficit because of the AIDS crisis that has been taking place last year. So statistically, we are impoverished by this problem, and we need emergency help. The local tax base can no longer afford to pay for the health care that is needed in this workingman's district and apparently, being in the middle of Newark and New York and being just part of this contiguous area, we touch both cities, to leave out of the equation Jersey City and Hudson County would be a tremendous injustice. I would plead to you that the emergency that is required in this area for funding to stem this problem, particularly with the children and particularly with the growth that we have, is one of the most urgent things that have been brought to my attention while I have been in Congress.

So I really want to press very, very hard and I want to put into the record the statistics of the Medical Center, which I would ask—already my remarks have formally been put in, I believe, at the time that Senator Lautenberg testified, and also a description of the services—of the Jersey Medical Center that were given regarding AIDS.



It is a most egregious problem. It really is defiant of any kind of answers that we are able to afford from the local basis. The help of the Federal Government is crucial and critical and I plead with you to make an amendment that would be tailored where 0.2 percent AIDS level per capita would be entitled to this section under title III of your emergency bill.

We now have 0.26 percent. There is no other community in the country that would qualify with that level, I am informed by statisticians. Inasmuch as we know that the emergency has not been abated. It is even growing at a point that we have become tremendously alarmed, and our health authorities are all alerted and our population is really living in fear of this scourge that is wiping out a part of our society and our community.

So I wanted to take my time out from the Budget Committee to come here and to personally tell you how important it is to the 540,000 people of our community and the spillover that would occur from the other communities if you don't contain the problem with our community. It would be enormous and your attention to this problem, this amendment, would be greatly appreciated.

[The prepared statement of Mr. Guarini and statistics of Jersey City Medical Center follow:]

#### STATEMENT OF HON. FRANK J. GUARINI

Chairman Waxman, I am pleased to be here this morning to give my strong support for your bill, H.R. 4470, the AIDS Prevention Act of 1990.

Mr. Chairman, I have deep respect for your work in the area of AIDS research. Throughout your career, you have championed the fight for AIDS prevention and treatment and pushed Congress to confront the many urgent health problems affecting our nation's urban poor. Your leadership is needed now more desperately than ever as we step up our fight to prevent the spread of AIDS and ensure that all Americans have access to adequate health services.

I also want to take this opportunity to thank my colleague, Senator Frank Lautenberg, for all the work he has done to help Hudson County get the support we so urgently need to fight AIDS in New Jersey.

As a representative of one of the nation's worst AIDS-infected regions, I want to thank you for introducing this bill and urge you to ensure that Hudson County is included as a recipient of emergency funding under Title III of this proposed legislation.

My district has the 4th highest per capita AIDS rate in the country. As I am sure you read in the letters you received from Senator Lautenberg, Hudson County Executive Robert Janiszewski, and myself, this per capita rate is 5 times that of Chicago and 2½ times that of Washington, D.C. Between 1988 and 1989, the number of AIDS cases in Hudson County increased by 78 percent.

The 1,428 AIDS cases documented this past year represent 0.26 percent of the Jersey City PMSA population of 542,000. Only two of the 10 areas that do currently qualify have a higher incidence rate.

Mr. Chairman, Hudson County desperately needs this funding. If our AIDS rate continues to increase at its current rate, it will pass 2,000 in another year. I don't think anyone here wants to wait for that to happen.

Today, Senator Lautenberg and I are proposing an amendment that would enable a metropolitan area with a population of 500,000 or more with an AIDS rate that exceeds 0.2 percent of the population to qualify for emergency funding under your bill.

Mr. Chairman, I wouldn't be here today if I did not truly believe that Hudson County needed emergency assistance. My entire community has made a monumental effort to stop the spread of AIDS. The Jersey City Medical Center, local leaders, and community health organizations have worked hard to educate people about AIDS and help all who need treatment to get it quickly. But we are still falling further and further behind.

Your bill would enable Hudson County to increase and improve outpatient services to low-income individuals and families infected with AIDS, prevent unneces-

sary—and expensive—inpatient services, and help patients obtain the most appropriate type of care they require. While the assistance the bill would bring into our district would not solve our AIDS problem overnight, it would go far to bolster our effort to treat more people and prevent new cases.

I hope you will consider our proposal favorably. Thank you for allowing me to testify before you today.

#### JERSEY CITY MEDICAL CENTER INPATIENT AND OUTPATIENT AIDS UTILIZATION STATISTICS AND ACTIVE GRANT AWARDS, FEBRUARY 27, 1990

##### Inpatient Utilization Statistics

Year	No. AIDS admissions (percent of total)	No. AIDS patient days (percent of total)	AIDS Length of stay (in days)
1987 .....	392 (2.2%)	7,900 (5.8%)	20.2
1988 .....	429 (2.3%)	8,407 (6.4%)	19.6
1989 .....	474 (2.4%)	9,433 (6.8%)	19.9

##### Outpatient: Utilization Statistics

Program	Number of visits			
	1986	1987	1988	1989
Infectious Disease .....	545	1,170	2,074	3,379
AIDS Health Service .....		2,801	4,180	6,240
Confidential Testing Service .....	2,941	3,248	3,972	4,728
Treatment Assessment Program .....				1,836
Pediatric Infectious Diseases .....	62	124	248	496
Neonatal High Risk Clinic .....	N/A	N/A	N/A	86

##### Active Grant Awards

Funding agency/title	Total award	Fund period
Robert Wood Johnson Foundation/Maternal & Infant Health .....	\$550,301	6-1-88 to 5-31-90.
Robert Wood Johnson Foundation/AIDS Health Services .....	548,541	1-1-88 to 10-31-90.
State of New Jersey Department of Health/Regional Pediatric HIV Treatment Center .....	142,872	8-1-89 to 7-31-90.
State of New Jersey Department of Health/AIDS Consultation Treatment Services .....	75,000	7-1-89 to 6-30-90.
State of New Jersey Department of Health/Counseling and Testing Site for HIV Antibodies.	421,662	1-1-90 to 12-31-90.
State of New Jersey Department of Health/Treatment Assessment Program [TAP] Demonstration.	250,000	10-2-89 to 6-30-90.

#### JERSEY CITY MEDICAL CENTER DESCRIPTION OF AIDS SERVICES

**AIDS Health Services [AHS].** AHS is a comprehensive, interdisciplinary case management program for HIV positive patients that provides supportive counseling and health education. AHS currently manages the care of 600 patients.

**Confidential Testing Service [CTS].** JCMC's CTS, one of fourteen federally funded sites, provides confidential and anonymous HIV testing and pre- and post-test counseling. Approximately 100 patients per week are counseled at the CTS and 22 percent test positive for HIV. Eighty percent of CTS patients are first time patients to the Medical Center.

**Infectious Disease Service [IDS].** IDS provides medical services to HIV positive inpatients and outpatients and is involved in experimental drug trials and other research. IDS manages the care for approximately 50 inpatients per day and outpatients seen in the AHS.

Treatment Assessment Program [TAP]. JCMC's TAP, one of four located in New Jersey, provides early outpatient intervention and initiation of treatment protocols to asymptomatic HIV positive patients to control the onset of symptoms. The program accepts referrals from the CTS and other community agencies. The goal of TAP is to make effective use of community resources and minimize the reliance on acute care services.

Neonatal and Pediatric Services. JCMC offers a wide range of HIV-related services to newborns and children. High risk infants receive regular developmental assessments, HIV testing, well-baby care and treatment of HIV-related illnesses. Approximately 60 children are now followed in the outpatient clinic, a 200 percent increase over the previous year.

Outpatient Obstetrics and Gynecology [OB/GYN]. OB/GYN identifies high risk pregnant women and offers HIV testing when indicated. Patients who test positive are referred to the neonatal clinic for followup. In the last six months, 258 women were identified as high risk.

Mr. WAXMAN. Thank you very much, Mr. Guarini. You are absolutely right when you talk about the overwhelming burden that your community and some of these communities that are hard hit by the AIDS epidemic—that burden is one that can destroy the health care system and make them less able to deal with those problems. We want to take to heart what you said about Jersey City and to recognize the uniqueness of the problem there, which is not going to be so unique unless we do the kinds of things that we must be doing to deal with this epidemic, such as getting early intervention treatment to people who are poor and can't afford it, and making sure that these areas that have the heavy cases get emergency aid, including your area, and I know your work on the Budget Committee is going to be determinative of whether we are able to do any of these things, so you are absolutely right, they are not unrelated.

Thank you for your testimony and for bringing this point to our attention.

I don't know if any of our colleagues have questions of you, but let me see if they do.

Mr. Dannemeyer.

Mr. GUARINI. Bill.

Mr. DANNEMEYER. Frank, I appreciate your comments and I am pleased to say that on April 2, which is just a couple of weeks ago, the Medical Society of your home State, New Jersey, representing some 10,000 physicians in the State of New Jersey, endorsed H.R. 3102, a bill that I introduced last year to deal with controlling the AIDS epidemic. I suspect you may not be aware of that. I don't mean to put you on the spot—

Mr. GUARINI. But it didn't hurt us one bit.

Mr. DANNEMEYER. Yes. Were you aware of the fact that your Society has endorsed the bill that I introduced?

Mr. GUARINI. I am aware that the Medical Society is alarmed and greatly concerned over the AIDS that we have in our State and, although I didn't know of their specific endorsement, I do know of their activity and their concern.

Mr. DANNEMEYER. I suspect that we have a lot of things on our plate and I could certainly understand how that might have slipped by your things in your in box, but I want to share that with you because I think it is an important step. That is the seventh State medical society in the country that has endorsed my bill.



New York, Massachusetts, Maine, South Dakota, Arkansas and West Virginia are among the other States.

It is significant because New Jersey, as you know, has the fourth largest number of AIDS cases in the country. New York State has the most. My State, California, is second.

Mr. GUARINI. Per capita, we are really way ahead of many other areas.

Mr. DANNEMEYER. The reference of largest number is totals and percentagewise. That statement is true both for California and New Jersey. But the significance of H.R. 3102, and I know you have got a lot of things on your plate like the rest of us to think about and study, but the cornerstone of that bill is reportability for HIV carriers and contact tracing because I noticed, with interest, what you emphasized in your comments. We have to do something if we can to prevent the transmissibility of this disease to other people.

The tragedy for the vast majority of the lay men and women in America is that we have been disserved or unserved or badly served by the leaders in certain medical professions of the States of the Union and, in my judgment, even by people serving in the U.S. Public Health Service. We have permitted ourselves, for good or bad, to be put into a position where we have emphasized the civil rights of the infected and ignored the civil rights of the uninfected.

Mr. GUARINI. That is true.

Mr. DANNEMEYER. That is why I emphasize the importance of H.R. 3102, because it implements what, in my humble opinion, our country should have been pursuing at the State level routinely from the early stages of the epidemic, namely that we say to those who are infected, you have a responsibility to the rest of the people of the country not to infect them with this tragic disease and that is the whole concept of reportability.

Mr. GUARINI. We saw this coming, but we have done very little about it to really meet the challenge that we had.

I was at the Pasteur Institute in Paris and we were really asleep at the switch for a long time and that is why we got behind the curve in this fight against AIDS. I think now we can do something about it.

Mr. DANNEMEYER. I share those thoughts with you.

Thank you for your testimony.

Mr. GUARINI. Thank you, Bill.

May I just make one mention, Mr. Chairman, in regard to what Mr. Dannemeyer said. We have, in Jersey City, in Hudson County, five times the epidemic rate that they have in Chicago, per capita. We also have two and a half times the per capita rate that exists here in Washington, D.C., which has a tremendous IV problem in and of itself. So it gives you the magnitude of what we are facing in my community.

Mr. WAXMAN. Thank you very much.

Dr. Rowland.

Mr. GUARINI. Roy.

Mr. ROWLAND. Frank, thank you very much for coming. I appreciate it and you certainly do focus on a good point. In Georgia, there is a tremendous increase, percentagewise, in the number of HIV-infected individuals and the numbers of AIDS cases also.



Those impacted cities, while they have the largest number of AIDS cases this time, certainly much consideration needs to be given to those areas that have less than that number that is specified in the bill, and we will certainly be working to address that.

Mr. GUARINI. Thank you very much, Roy.

Mr. WAXMAN. Mr. Nielson.

Mr. NIELSON. Frank, I would hope you will stay long enough to hear Dr. Rockett's testimony because her testimony—I was just reading it—is one that says H.R. 3102, Mr. Dannemeyer's, and H.R. 4470, Mr. Waxman's, are complimentary and help each other and you need some elements of both in order to solve the problem. I hope if you don't have time to listen to her testimony, you will pick up a copy of it because it is rare that you can find Dannemeyer and Waxman agreeing on anything or any portion of any thing—

Mr. GUARINI. America comes together on this one, I am sure.

Mr. NIELSON [continuing]. With all due respect to the two gentlemen on my right.

I think it is very—I am looking forward to her testimony and I hope you will pay attention to it, too, because I do think we do have to protect confidentiality, but we also need to stop the disease and we need to spread—at least to the sexual partners, at least to the married spouse and the children at least ought to be involved in my view.

Mr. GUARINI. Thank you. I have my staff monitoring this hearing and I will request a copy of your report, Doctor, and I will promise you that I will look through very carefully, and I appreciate your attention.

Thank you very, very much.

Mr. WAXMAN. Thank you very much, Mr. Guarini.

Dr. Rockett, we are pleased to call on you at this time for your testimony.

#### STATEMENT OF BARBARA A. ROCKETT

Ms. ROCKETT. Thank you, Mr. Chairman, and members of the Subcommittee on Health and the Environment. As a past president of the Massachusetts Medical Society and speaking on behalf of the over 14,000 members of this organization, it is indeed my pleasure to appear before you today to speak in support of the courageous legislation which is being proposed to help us address and control the devastating effects of the AIDS epidemic which is sweeping our country.

In December 1989, as has been mentioned before, the House of Delegates of the American Medical Association, with the support of the entire Massachusetts and New England delegations—and I might add, in the New England delegation, six States are represented—overwhelmingly voted to embrace a public health strategy to control the epidemic of HIV infection in this country.

There was a recognition on the part of this body that truly heroic measures would be needed if we were to bring under control a plague which is threatening to undermine the very foundations of our social structure. We all recognize that the escalation of health care costs, for whatever reasons and from whatever sources, is already beginning to reduce critical access to health care, access

which has been the hallmark of our social structure and the linchpin of an effective health care system.

AIDS has dramatically increased health care costs and, unless controlled, will further distort the inequalities in our health care system with which this Congress and our State legislatures must continue to struggle. The legislation which has been proposed, H.R. 3102, by Congressman Dannemeyer of California, and H.R. 4470, by Congressman Waxman of California, although differing in several significant respects, appropriately elevate these critical issues to the level of public policy debate, and upon resolution and acceptance by the Congress, will contribute significantly to the solution of this problem.

While differing in some aspects, I view the two bills as more complimentary than conflicting. The physicians for whom I speak believe there are critical elements that any legislation must address if it is to be successful in this effort. These elements include early testing, routine testing in a variety of high-risk settings, routine reporting with assurance of confidentiality, contact tracing, aggressive partner notification, and penalties for knowingly transmitting the disease. We believe the elements which I have listed are essential for the successful implementation of any legislation.

With your permission, let me elaborate on the reasoning for including these elements. A basic epidemiologic premise underlying these elements is the recognition that HIV infection must be managed as any other infectious disease has been managed in the past. Early testing, resulting in early identification of HIV-infected patients, has proven beneficial because of the increasingly demonstrated efficacy of early intervention with newly available medication, developments that have significantly prolonged life in those suffering from this disease. Earlier identification will provide an opportunity for earlier counseling for the patients and their families.

In certain circumstances, the delay engendered by the need for written consent should be abrogated in order to extend the benefits of treatment and disease control to as wide a population as possible. We feel that innocent victims, including children and partners, must be provided the utmost protection from infection by this devastating illness.

By the way, I trained at a major city hospital, Boston City Hospital, and I now hear that this public health—in this public health, 25 percent of the babies born at that public health are infected with the AIDS virus.

In addition, particularly in medical and other high-risk settings, such as prisons and during premarital serologic evaluations, we believe that the protection of the innocent makes it critical that the potentially infective individual be recognized in order that proper precautions might be initiated.

Again, one of the principles from which has emanated such significant advances in the control of other sexually transmitted diseases is the practice of aggressive contact tracing. Contact tracing can only be implemented with a well-developed public health system of confidential reporting. Inherent in this mandate must be the basic principle of confidentiality and protection of the rights of all involved.



Penalties for those individuals who knowingly spread the virus should be supported. Although it is inconceivable to you and to me that individuals would knowingly infect innocent victims, unfortunately, we still recognize that such actions do occur.

As a physician involved in the clinical practice of medicine—as a matter of fact, I am a surgeon and my husband is a neurosurgeon. I have two sons in medical school, both planning to go into surgery. Let me take 1 minute to expound on my personal concern, and that of my colleagues, regarding the HIV risks inherent in our daily activities.

Not only do my colleagues in clinical practice approach every day with anxiety, I am finding it increasingly difficult to recruit, stimulate and encourage young people to either enter or remain in the medical and nursing professions.

Mr. Chairman, and members of this committee, may I express my appreciation for the opportunity to appear before you and to speak in support of your efforts to address this devastating epidemic which we are encountering. I realize, as I know you do, that public policy issues of this magnitude will require courageous men and women dedicated to the well-being of our country to find a solution. I would like to thank you very much for being able to appear before you and we in the medical profession probably are closer to the problem and as close as the families and the infected individuals.

Thank you very much.

Mr. WAXMAN. Thank you very much, Dr. Rockett.

I want to thank the four of you for your testimony. The four of you have been invited to testify at the request of Mr. Dannemeyer to talk about the issue of reporting the cases and to have contact tracing.

You might not realize this, but I don't have any disagreement with the points that you just outlined as essential to try to deal with this disease.

Ms. ROCKETT. I realize that.

Mr. WAXMAN. Where we have a disagreement is not whether there ought to be reporting or whether there ought to be contact tracing. The disagreement is whether we are going to say, the first time and for the first disease, that the Federal Government is going to tell everybody in the country how to deal with it.

Right now, for any other communicable disease, we leave it up to the States to decide how to handle the reporting and the contact tracing. I have no doubt that it is important to get people in to be tested, to be counseled, and to contact those with whom they have had sexual relations to get them in as well to be tested and counseled so that we can give them early intervention to prevent AIDS, developing with that individual, and also to try to keep them from acting in ways that will further spread the disease.

But we don't mandate every State to do this. We leave it up to the local governments to decide and the local governments have different kinds of problems. There is a different problem in New York and New Jersey than there is in Arkansas and other places in the country.

We think they ought to make the decisions on how to handle this matter, but we don't have a disagreement as to whether we ought to be reaching out as much as possible.

There is also concern that has been expressed that we don't want to drive people away. We want to get them in. We want to get them in in New York and get them tested so you can find out what is going on and how to deal with the epidemic in a realistic way.

So I think we have to be sensitive to that. But while you are here—I know you are here to speak about the contact tracing and the reportability aspects, do you all—or do any of you disagree with the idea that the Federal Government ought to be providing funds for testing and counseling?

Mr. Lisa, do you disagree with that?

Mr. LISA. What I am afraid of, Congressman Waxman, is this: What we will be doing, if we pass H.R. 4470 in its present form, is we will be placing the ability of the taxpayers of the Federal Government to provide funding in the State of New York that will add legitimacy to a statute that is not working in New York.

Mr. WAXMAN. Let me stop you because I really——

Mr. LISA. Contact tracing——

Mr. WAXMAN. Excuse me, Mr. Lisa.

Mr. LISA. Yes.

Mr. WAXMAN. You have talked about contact tracing. Do you think we ought to provide funds for testing and counseling programs? Yes or no?

Mr. LISA. Oh, absolutely.

Mr. WAXMAN. That is the question I wanted.

Dr. Jones, do you agree——

Mr. LISA. But——

Mr. JONES. Absolutely, I agree.

Mr. WAXMAN. And Dr. Schwartz?

Mr. SCHWARTZ. I absolutely agree.

Mr. WAXMAN. Dr. Rockett.

Ms. ROCKETT. I agree. I don't think AIDS should be treated as a special disease other than others, as has been mentioned earlier by your earlier panels, but I do think we have to have a broad ability to test, otherwise we will not be able to have identification and early treatment.

Mr. WAXMAN. Do you feel it is important that we provide funding for early treatment——

Ms. ROCKETT. Yes, I do.

Mr. WAXMAN [continuing]. Under the Medicaid program or at the grants?

Ms. ROCKETT. Yes.

Mr. WAXMAN. Do any of you disagree with that proposition? Because while you here to talk about the contact tracing, I did want to get the benefits of your thoughts on this issue on the record because the bill deals with that question as well.

The bill also has provisions for funds for areas in hardest impact with AIDS cases, just as we give emergency money for areas that have earthquakes and hurricanes and other natural disasters.

Do any of you disagree with that notion?

Mr. LISA. Mr. Waxman, this money is desperately needed in New York. We are going to lose in the next 10 years, more New Yorkers



to AIDS than all of the Americans that were killed in Vietnam, Korea, World War II and World War I put together. We are the major epicenter in the western hemisphere for this epidemic, but in addition to the money, we need to put some of the science into the epidemic and take some of the politics out.

We have to have contact tracing and contact notification. It does work. The presenters at the 5th World Conference on AIDS last year in Montreal, in their workshop—and I would be grateful if you would allow me to contribute to the committee's deliberation, the videotapes of both the workshop and the round table discussion—proved to my satisfaction that contact tracing, contact notification works. It does prevent and does slow down the uncontrolled spread of the epidemic.

With anywhere between 200,000 to 400,000 HIV-infected and infective adults in New York City, we have to use that tool. Giving us that money is something that we desperately need, but you must give us something more. You must give us some protection for the public health.

Mr. WAXMAN. Certainly we need to give you protection and you at the local level have to provide protection for the public health. I don't disagree with contact tracing. I don't disagree with trying to reach people to have them come in and be tested. My question, in my mind, and I am not asking because my time is expired, is whether the Federal Government has to tell the people in New York to handle their problems one way, the people in Arkansas the same way, and not give them some flexibility to think that it may be more effective to use other strategies.

My time is expired and I want to recognize Mr. Dannemeyer.

Mr. DANNEMEYER. I thank my chairman for his comments. I find it interesting, preliminarily, Mr. Waxman, that you are expressing this concern on mandating reportability by the Federal Government for HIV carriers, yet your bill mandates that States which receive Federal money have in place laws that require providers to obtain written consent before an individual can be tested for HIV.

Also, your bill mandates certain regulations regarding counseling. So I am just raising the question, if it is appropriate to require States to follow your written consent and counseling requirements as a condition of receiving Federal money. I would suggest it is also appropriate to mandate that when States get money from the Feds, they implement policies that deal with preventability, namely reportability and contact tracing.

Dr. Jones, you have——

Mr. WAXMAN. If the gentleman will permit and yield to me, we are giving the money for a specific purpose.

Mr. DANNEMEYER. Yes.

Mr. WAXMAN. We are saying here is money to do counseling. I don't think it is unreasonable to say if we are giving money to do counseling, use the money for counseling. We are not giving money to do the contact tracing. We are saying to the States, cities, use the block grant money for New York how you see fit. You have the heavy burden of care; you have the heavy burden of the epidemic. We are not spelling out how to use that money. Use it as you see appropriate in your area.

In New York, they may well decide to use that money differently than in San Francisco or Jersey City, and I think it is reasonable for us to say to them, do that which you think most appropriate to do with the money.

Mr. JONES. Chairman Waxman, before Mr. Dannemeyer—

Mr. WAXMAN. I have to yield to Mr. Dannemeyer—

Mr. DANNEMEYER. I yield to Mr. Jones for a comment to my colleague there.

Mr. JONES. Mr. Waxman, I would like to point out to you that written consent is another example of how the HIV epidemic, as you would have it done, would be—rather, we would treat the HIV epidemic differently than we do any other thing in medicine. Physicians have been and should continue to be allowed to make the decision when a written consent is desirable, and to put that in your legislation is unacceptable to me and to the basic policy of the American Medical Association. It should be left to the discretion of the physician.

Thank you, sir.

Mr. DANNEMEYER. Dr. Jones, you had an interesting experience as a participant in the convention of the American Medical Association last December in Hawaii dealing with the adoption by the AMA of a resolution on the issue of reportability. Would you share that with the members of this subcommittee and all of us here today, please?

Mr. JONES. It has just been my belief from my training days on that reportability and contact tracing are an invaluable tool in the intervention before the disease process begins. It has always appalled me that organized medicine was not straightforward in stating that principle.

At the AMA meeting, I was able to solicit and develop an enthusiastic response of the 1,400 delegates assembled to pass the recommendations that are now part of the AMA policy.

Mr. DANNEMEYER. What is that specific recommendation?

Mr. JONES. The specific recommendation is that the—that HIV seropositive individuals—I am not reading it, I am recalling it from my construction of it—that seropositive individuals be reported to the health departments of the 50 States for the purposes of contact tracing and partner notification and it was strongly recommended and that we strongly recommended a system of contact tracing, partner notification be implemented in the various communities in the country.

Mr. DANNEMEYER. Thank you very much.

Dr. Rockett, you have been active—I think you mentioned you were a delegate to the convention in Hawaii as a representative from New England. How did it also—how was your involvement there—were you speaking on behalf of the other New England States that you made reference to in that capacity?

Ms. ROCKETT. We had a separate meeting of the New England States and, in fact, Massachusetts reviewed your bill, Congressman Dannemeyer, and wholeheartedly supported it, the entire Massachusetts Council, which is comprised of over 400 physicians, and they were speaking on behalf of the 14,000 physicians in Massachusetts.



This was brought before the New England delegation, comprised of the six New England States, and they also endorsed this.

As a delegate to the American Medical Association, I know Dr. McGrath will be speaking on behalf of the American Medical Association later. I actually served on the Public Health and Scientific Affairs Committee, so I was one of the members of a committee of, I think, five people who reviewed this and the testimony lasted—probably the longest that I have known at the American Medical Association, people were so interested in this. It began very early in the morning. We left after 5:30 at night, spent the rest of the evening, went into the morning and again resumed early in the morning. This was such a—I could describe it hot issue, that the people involved, when they heard the reasoning for it, overwhelmingly supported the parts of this bill, parts of the resolution, if I could correct that, the American Medical.

Mr. DANNEMEYER. Thank you very much, Dr. Rockett.

Mr. WAXMAN. Dr. Rowland.

Mr. ROWLAND. Thank you, Mr. Chairman.

Will you say that all of the medical community in this country is concerned with the spread of HIV, the epidemic that we are facing in care for people who already have the disease? Isn't that the thing that we are all concerned about and that we all want to deal with?

Is there some disagreement in the medical community and in our public health officials about how to do this? We talk about testing and contact tracing, that it is felt by some individuals that it should be on a voluntary basis and it is felt by other individuals that it ought to be mandatory.

Medical science is not an exact science, I think we all agree to that, that there are variables and that we debate issues in the medical community when we disagree and there is some disagreement here.

What I would like to sort of focus on a little bit—you are here specifically relative to contact tracing—is the difference, if you perceive a difference, between HIV infection as a sexually transmitted disease and other sexually transmitted diseases. Is there a difference between these diseases and should we address them with a different policy?

Mr. JONES. I will answer that very briefly and loudly. It should not be treated any differently.

Mr. ROWLAND. Is it different?

Mr. JONES. It has been treated differently from—

Mr. ROWLAND. Is the disease itself different?

Mr. JONES. Oh, well, the disease itself is a viral disease and although there are sexually transmissible diseases that are viral, there are treatments that are efficacious in treating and curing the disease. I am sometimes asked, will we ever have a antiviral agent that will kill the virus of HIV, and you have to ask yourself, do we cure the common cold with a drug? Do we cure measles with a drug? Do we cure herpes simplex with a drug? We control those processes. We make them go dormant.

As I sit here today, I still feel that probably our answer will be control, keeping that person's virus locked up, if you will, for the duration of his life, but not necessarily eradicating the infection.

Mr. ROWLAND. You mentioned herpes as a disease that is not curable.

Mr. JONES. That is correct.

Mr. ROWLAND. What is the difference between herpes and HIV?

Mr. JONES. Herpes is a virus—

Mr. ROWLAND. I mean, what is the difference in the outcome between herpes and HIV?

Mr. JONES. Before HIV became a public discussion, you recall several years ago, the virus microscopically photographed, the microscopic picture of the virus—

Mr. ROWLAND. I am not talking about the—

Mr. JONES. What I am saying is—

Mr. ROWLAND [continuing]. I am talking about the outcome.

Mr. JONES. The outcome?

Mr. ROWLAND. What about the difference—

Mr. JONES. The outcome in the HIV epidemic is that everybody that gets it at this point, 90 percent are expected to succumb to the disease and most people think even 100 percent.

Mr. ROWLAND. What about herpes?

Mr. JONES. It kills babies who are infected during delivery and it is an inconvenience at most. I think it is extremely exaggerated as a public health hazard.

Mr. ROWLAND. So there is a difference, isn't there?

Mr. JONES. Absolutely.

Mr. ROWLAND. There is a difference between herpes and between HIV infection—

Mr. JONES. Yes.

Mr. ROWLAND [continuing]. But you put them in the same category a few moments ago by saying that they are both incurable.

Mr. JONES. No, I didn't get a chance to finish my—I think it would take too long to explain that to a layman, sir.

Mr. SCHWARTZ. Mr. Rowland—

Mr. ROWLAND. I will try to understand.

Mr. SCHWARTZ. Might I interject something? As far as communicable and sexually transmitted diseases that are conveyed by virus, the greatest difference between AIDS and the other diseases is that the end point of AIDS is death. The end point of the other diseases may be some disability or no disability at all, and that is the big point.

If we are going to treat these other diseases that don't result in death as communicable and reportable, why not do it with a disease that will eventually kill and does, as I have given you the numbers. 125,000 cases, 70,000 of which have died to date. You come back in about 5 years and I will tell you what, 124,000 of them or more will be dead by that time.

Mr. ROWLAND. There is a difference, then, isn't there?

Mr. SCHWARTZ. Absolutely.

Ms. ROCKETT. Could I respond to part of your question, Dr. Rowland?

Mr. ROWLAND. Please.

Ms. ROCKETT. One of the comments I would like to make is a personal comment. I, in fact, served on the AIDS Commission in Massachusetts and there was a great deal of energy put into raising funds for research, addressing this and yet there was vigorous op-



position to mandatory reporting and mandatory contact tracing. This puzzled me because the greatest way to control it would be to implement these factors.

Perhaps I am conditioned this way, having been trained at a city hospital in Boston, and in all hospitals in Massachusetts, where everyone who entered had to have a hidden test for syphilis, had to have a chest x-ray for tuberculosis in order for us to institute treatment. Some of the people who had tuberculosis, you might say were discriminated against because they were put into sanatoria to be treated. But on the other hand, it was the only way to control it.

Mr. ROWLAND. Those are curable diseases.

Ms. ROCKETT. That is right.

Mr. WAXMAN. The gentleman's time is——

Ms. ROCKETT. And we hope AIDS will be.

Mr. WAXMAN. The time has expired.

Mr. Nielson.

Mr. NIELSON. Yes. I am very impressed with your testimony, Dr. Rockett. I gave you a public plug there.

Let me ask you one question on the point you make on the next-to-the-last page of your testimony. You say:

As a physician involved in the clinical practice of medicine, let me take 1 minute to expound on my personal concern and that of my colleagues regarding the HIV risks inherent in our daily activities.

The next paragraph is important:

Not only do my colleagues in clinical practice approach each day with anxiety, I am finding it increasingly difficult to recruit, stimulate and encourage young people to either enter or remain in the medical or nursing profession.

Would you like to elaborate on that?

Ms. ROCKETT. I would be very happy to, sir.

Mr. NIELSON. You didn't have time in your testimony.

Ms. ROCKETT. Right.

I am a graduate of Tufts Medical School, a graduate of Wellesley College. My husband graduated from Tufts Undergraduate and also Harvard Medical School. We have voluntarily returned to our schools to teach some of the students because we think it is our duty to teach some of those coming along.

We will often drop the set curriculum that day because the students come in and express their fears and their concerns about whether they want to continue on in the practice of medicine. I happen to have two sons in my home, so we don't leave it at that school. We go home and we listen to this at home.

Our second son, who graduated from Harvard and is at my alma mater, Tufts Medical School, comes home daily saying, "Do I really want to go into medicine?" We have talked with him and we say, "What are your concerns, Sean," and his concerns are, one of the major ones, contact and infection with AIDS. He looks ahead at his life and says, "Do I want this to happen?"

More so than that, I go into the operating room almost daily and those nurses have no idea of who might be HIV-infected are dealing with this. We now have to purchase goggles, shields, any number of things, but we want to institute more protection for our medical personnel because we think they are innocent victims if they don't know in advance.

Mr. NIELSON. Is this also true of the Dental Association?

Ms. ROCKETT. Oh, absolutely, as well. Not only that, but lab technicians, radiology technicians, anyone coming in contact with bodily fluids right now. We have to give them that protection. If we don't know who has the disease or the infection or is HIV-positive, how can we do this?

Mr. NIELSON. If you in the medical profession are—who have ways of becoming aware whether they have HIV or not, if you are concerned and you are worried, how much more would the average person who doesn't have the possibility of finding that out—how much more might he be concerned in his everyday contacts?

Ms. ROCKETT. Now you can see why our numbers have diminished. I happen to come from the home of mandates, usually, and on the other hand, this one—and that is the State of Massachusetts—this one is not being mandated and if we share that information with someone, we are legally responsible and I think that is wrong.

Mr. NIELSON. Okay.

I like the way you list the elements required for any kind of problem. You say early testing. We all agree with that. Routine testing of voluntary—in a variety of high-risk settings.

The next four are the heart of the H.R. 3102 bill: routine reporting with assurance of confidentiality; contact tracing; aggressive partner notification and penalties for knowingly transmitting the disease. I commend you for those statements.

Let me ask Dr. Schwartz, in New York, you do have a provision that you can notify the partner if you are convinced that the individual with AIDS is not going to do so or will not do so. How many doctors in New York have actually done that?

Mr. SCHWARTZ. I really don't know, but there is—Chairman Lisa can respond, but I do know this: that you cannot do it unless you have the absolute permission of the patient to then go on to contact tracing.

Mr. NIELSON. And that requires a possibility of suit if you do it and then—

Mr. SCHWARTZ. Yes, it does.

Mr. NIELSON [continuing]. And if he finds out—or she finds out that you have told the spouse, then you can be sued. Is that correct?

Mr. LISA. May I address that?

Mr. NIELSON. Yes, please.

Mr. LISA. The New York State statute has very chilling provisions that apply against a physician who makes a bad judgment call. A physician in New York may only notify a spouse or a contact of a patient that tests positive if that physician has reason to believe that the patient will not so notify the individual. If the physician makes a bad judgment call, that physician can be sued civilly—the statute creates a civil suit that never existed before and can be prosecuted for a misdemeanor crime—the statute contains a criminal prosecution provision that had never existed before.

So, with those chilling provisions, it would not surprise anyone when I tell you that in this city that has more cases of HIV infection than anywhere else in the entire western hemisphere, in the one year that the statute was in effect, not one single physician,



private physician, referred one single name to the New York City Department of Health for contact tracing and partner notification.

Mr. NIELSON. May I ask one more question, Mr. Chairman?

Mr. WAXMAN. The gentleman can proceed—well, we will have a second round, so I think to be fair, we ought to—

Mr. NIELSON. All right. I will wait then. Thank you.

Mr. WAXMAN. Mr. Dannemeyer, why don't you go with your second round.

Mr. DANNEMEYER. Thank you. I would like to ask Dr. Schwartz, I think the story of New York State, with the largest number of AIDS cases in the country, needs to be told across America. I am referring to the struggle between the leadership of the voice of organized medicine, the New York State Medical Society, and the chief health officer of the State of New York, Dr. David Axelrod.

Now, you alluded to that earlier, but would you tell us a little about that problem that exists between the chief health officer, Dr. Axelrod, who works for Governor Cuomo, the last time I noticed, and the position of the State Medical Society of the State of New York?

Mr. SCHWARTZ. We, as obstetricians, felt that the pregnant patient, the new fetus, was being done a disservice by not knowing where or who was infected with the disease. We tried to prevail upon the Commissioner to make this a communicable and reportable disease so that it could be treated as any other disease that is of the same nature.

He refused. We then—

Mr. DANNEMEYER. You are talking about Dr. Axelrod?

Mr. SCHWARTZ. Yes, Dr. David Axelrod. He refused. We then instituted a suit and we were joined by a number of other societies.

It took quite some time before the suit was answered in court, but we were—we lost the initial suit. We are now pursuing the suit in the court of appeals because he is very adamant about not declaring it a communicable and reportable disease. However, he did allow certain provisions, as Councilman Lisa mentioned, but his stringent requirements about reporting it make us very fearful.

As you will realize now, we probably have the largest malpractice rates, particularly obstetricians, in the country. We pay over \$91,000. If we were to get involved with this reportability of the malpractice—the reportability of the AIDS the way it is outlined now, our insurers would probably go broke and we couldn't be insured anymore.

So, as a result of which, you have heard not one case has been reported. We are damned if we do, we are damned if we don't, so we just let it ride by.

Mr. DANNEMEYER. What legislative body adopted this law that you described? Maybe Mr. Lisa could refer to that.

Mr. LISA. If I may, this legislation was adopted by the New York State Legislature, of which I had the privilege of serving as a member of the Assembly for 8 years. I think it was a terrible, terrible mistake and I have called and I have attached to your packet, by way of resolution from the city council, that they modify this statute. I think it has to be changed. I think it is just a question of time.

You see, the terrible problem about it is that the public hasn't seen the HIV infection epidemic yet. By the time we see the infections and illness, it is too late for too many. When the heterosexual population wakes up in New York City, they are going to demand to know who was in charge when this happened? Who was the steward? Who was on watch? Who was driving the bus? That will come. Just like we are hearing today, what all of us who have watched this epidemic for many years knew years ago, that we are in crisis. It shouldn't be a surprise to northern New Jersey. We knew this a few years ago, that this was coming.

The problem with this epidemic is that it remains invisible and silent in infections. When you see the illnesses, it is too late. We must take this action now.

I respectfully plead with you to seriously not endorse the practice in New York by allowing us to have this money that we desperately need without giving the people of the city of New York the protection of contact tracing and contact notification, along with the money. We need this desperately.

Mr. DANNEMEYER. Mr. Lisa, you also, I think, in your city, had a change in the position who is the health officer of the city of New York. What is the gentleman's name?

Mr. LISA. Oh, yes. Health Commissioner Stephen Joseph, and I have two copies——

Mr. DANNEMEYER. Joseph. Yes, didn't he make some interesting comments just on the eve of his departure from the job as the Health Director of the city of New York?

Mr. LISA. Well, in all fairness to Dr. Joseph, Dr. Joseph attempted to bring about contact tracing and partner notification at the 5th World Conference on AIDS in Montreal. Scientists from all over the world, 11,500, including myself, were denied the ability to hear what he had to say because of disruptions that took place. He was prevented from speaking and we were prevented from hearing.

Mr. DANNEMEYER. Who prevented him from speaking?

Mr. LISA. There were demonstrations by activists that took place at the conference. We all know that. That was on television, it was all in the newspapers.

Now let me tell you this, Dr. Joseph attempted to be able to bring about contact tracing and notification and I have his written comments, which I am pleased to supply to the committee.

[The prepared statement of Dr. Joseph follow:]

#### STATEMENT OF STEPHEN C. JOSEPH, COMMISSIONER OF HEALTH, NEW YORK CITY

I appreciate this opportunity to discuss the complex and necessary New York State AIDS confidentiality law, and the amendments to it that I believe are now appropriate.

This critically important law, which became effective on February 1, 1989, set forth parameters for testing for HIV infection, mandated confidentiality of HIV-related information and records, and permitted disclosure of the information in certain circumstances. It also permitted physicians to disclose confidential HIV information to a contact whom the physician reasonably believed to be at risk when the patient refused to notify the contact.

The protection of HIV-related information is of central public health importance. Prior to the law's passage, the HIV antibody test was not being used to anything near its maximum effectiveness. The confidentiality of the medical information generated by the HIV antibody test was easily superseded by subpoenas or general consents that were often obtained without consideration of the ramifications. The fear,



discrimination, and stigma associated with AIDS discouraged people from coming forward to seek counseling and testing on their own without legislative protection, and reduced the medical establishment's willingness to involve patients in counseling and testing programs.

Thus legislation protecting HIV-related confidentiality was a clear necessity. The New York State Legislature enacted a bill that is one of the strongest HIV confidentiality protections in the nation, and the Department of Health recognizes its critical value.

Since passage of the law, however, we have entered a "new epidemic." The federal Centers for Disease Control's recommendation that all HIV-infected persons be medically evaluated every six months, and other studies that have shown the benefit of early diagnosis of HIV infection and early access and entry into treatment for earlier forms of HIV illness and even asymptomatic infection, have increased the importance of even more vigorously offering widespread counseling and HIV antibody testing. These, along with the Department of Health's experience with the confidentiality law, suggest that changes to the law would increase its public health effectiveness. I would like to offer a number of specific changes based upon our experience.

First, as concerns Section 2781, HIV Testing:

(1) The requirement of Section 2781(c), that all possible disclosures must be explained before testing, together with some of the exceptions to confidentiality, has substantially inhibited testing in some medical and public health settings, such as tuberculosis and sexually transmitted disease clinics. The approved form for informed consent unnecessarily exaggerates the range and likelihood of disclosures that might occur without the protected individual's consent. Section 2781(c) should be revised such that the health care provider would be required to specify only those disclosures that are likely to be applicable; for example, a private practitioner's records are not subject to oversight agency review without consent. While this might be viewed by some as a retreat from complete informed consent, our experience shows that testing is inhibited by the excessively detailed informed consent; to comply with the intent of Article 27F, which was to improve testing and care, the law should be changed as suggested here.

(2) Many institutions and private physicians fail to offer HIV antibody testing to at-risk individuals. Certain medical institutions should be required by this section to offer HIV counseling and testing based on assessment of risk, including prevalence of infection in the institutional catchment area. This new provision should cover all facilities regulated by Article 28 of the Public Health Law. I strongly believe that physicians and health care institutions should be required to offer counseling and testing to all pregnant women because of the very high rates of perinatal transmission in the city and the state.

(3) When a serious exposure presenting a substantial risk of HIV infection occurs to public servants protecting society on a first-response basis, they should have as much information as possible. Section 2781 should be amended to authorize a court to order HIV-related testing, without consent, upon a showing that a police officer, firefighter, or emergency health care worker is at "significant risk of HIV infection as a result of exposure to" the person to be tested. The standards of evidence and proof should be the same as those high standards now required to obtain a court ordered disclosure of confidential HIV-related information (Section 2785).

Next, as concerns Section 2782, Confidentiality and Disclosure: Information gathering for the purposes of epidemiologic research should be completely confidential and should be protected similarly to research protected by Public Health Law Section 206(1)(i). The protection offered by Public Health Law Section 206(1)(j), as interpreted by the courts in the Love Canal cases, provides a significantly greater degree of protection.

Finally, as concerns Disclosure by Physician to Contacts:

(1) Section 2782(4), which establishes the physician's so-called permission to warn, has not worked. There have been no referrals to the New York City Department of Health by physicians since enactment of the law. Discussions with practicing physicians suggest that the physicians themselves are not notifying contacts either, but, if anything, are suggesting that patients tell partners or refer partners to the Health Department. Before the law was enacted, our reading of New York common law was that the physician had a duty to warn; Section 2782(4) was specifically crafted to replace that duty with permission. It now ought to be redrafted to require that the physician either ensure the patient has notified known contacts of risk, or notify such contacts or the Health Department; a "duty to have warned" must ensure that people at risk are warned.

(2) Section 2782(4)(b) further inhibits notification by physicians by apparently requiring the physician to personally disclose the information to a contact. This provision should allow for a trained agent to perform contact notification and counseling. Skilled professional staff who are competent to notify contacts and furnish necessary health care advice and counseling or make appropriate referrals include nurses, social workers, counselors, and physician's assistants.

These suggestions originate from the Department of Health. I will be proposing that they be submitted to the Legislature by the City of New York as legislative initiatives.

Some final comments regarding the control of HIV infection: Our increasing capacity to prevent and treat HIV infection obliges us to take more vigorous infection control measures, because we have clear health benefits to offer those who are infected. Early diagnosis of infection and illness is now to the benefit of both society and the individual. Our growing abilities to increase quality and length of life of HIV-infected persons give us a stronger case for, and an obligation to use, accepted public health measures for case finding. I believe that AIDS policies, buttressed by the AIDS confidentiality law, should shift to a disease control approach to HIV infection along the lines of classic tuberculosis practices. This has three major implications.

First, voluntary, medically confidential pre- and posttest counseling and HIV antibody testing, as required by the law under discussion today, should continue as the cornerstone of AIDS policy. But it must become routine in high prevalence areas in every clinical setting so that HIV-infected people can be identified and their treatment begun as early as possible. Anonymous counseling and testing should be preserved as an option for those who will not accept testing any other way.

Second, within a confidential public health framework, I strongly believe we should have, as is the case currently in 28 states, mandatory reporting of people who are infected with HIV. Doctors should be required to report the names of their HIV-infected patients to their local public health authority, as is required in tuberculosis.

Third, contact tracing should become more vigorous. The American Medical Association has recently drafted a resolution that strongly supports the concept of contact tracing in every community. Increasingly vigorous contact tracing in New York City would not infringe upon, but support, patient's and individual's rights, especially the rights of those most affected by the "new" epidemic of AIDS: blacks, Hispanics, women and children, and the poor and minority residents of New York who may not even know they are at risk of infection.

With these measures in place, supported by the law protecting confidentiality of HIV-related information, HIV-ill or -infected people would be able to receive appropriate medical treatment to prevent and treat their infections; appropriate and continuous medical followup; access to confidential and voluntary tracing and notification of their contacts, who can themselves seek counseling, testing, and treatment as needed; all within a noncoercive, nonpunitive setting that safeguards their privacy. All this will demand that needed services for HIV-ill people are available and accessible.

At a state legislative hearing on October 14, 1987, I introduced the concept of a physician's duty to warn in HIV infection. That debate was the starting point of the confidentiality bill that is under discussion today. I similarly believe that public health reporting of seropositives is a necessary and inevitable development. Today's hearing is an opportunity not only to continue shaping a confidentiality law that will support this critical public health measure, but to begin considering the legislative implications of public health reporting of seropositives. Otherwise we will lose our new opportunities to develop the fully effective programs, especially availability of massively expanded clinical and social services, that are so vital.

At this point, I would be happy to respond to questions.

Mr. LISA. May I just tell you this, Dr. Joseph's reasons were that the epidemic is increasingly becoming more an epidemic of families, of women, minority, poor, babies, adolescents. That is the future of this epidemic. The past of the epidemic were in gay men. The future of the epidemic in America is amongst American families. That is why contact tracing and notification must be put into place because it will work in this new population, in this new epidemic.

Mr. WAXMAN. The gentleman's time has expired.



Dr. Rowland, do you wish to be recognized?

Mr. ROWLAND. It really disturbs me to see part of our medical community in one area on this and part in another area. Voluntary versus mandatory or reporting and contact tracing.

We hear those who support voluntary concepts say that if we make it mandatory, that will actually keep people from coming in to be tested. There will be many people who won't come in that otherwise would come in, and the reason is because they will be discriminated against. That is, they will maybe lose their jobs or lose all of their possessions and my question to us is, is that a legitimate concern that these individuals have? Should we go ahead and do mandatory testing and tracing, taking a chance that maybe that won't happen?

How do we come down on this?

Ms. ROCKETT. Could I respond to that, Congressman?

If I could put it in the context of other diseases in the past, for example, tuberculosis, leprosy, Legionnaires Disease, polio, all of the life-threatening diseases, it took testing and it took identification and it took, finally, treatment with some of the simplest antibiotics to almost eradicate these diseases, as well as vaccines.

We need to have medical personnel available to treat these patients. Ethically, we, as physicians, will treat all and after all, the most important part of this equation is the patient. And in addition to that, I think we have to identify the illness. If we can't have testing, we can't identify the illness and certainly we have seen more recently that more treatments have become available, even a vaccine has been tested, or about to be tested. All of these things.

We are looking for a cure. We are not looking for just control. We want a cure, as far as this is concerned, and I think all of these things have to be put into effect. If I could suggest to some of you to read a book called, "Eleven Blue Men," and it had to do with public health types of procedures to control other infectious diseases, the tracing, the identification and, finally, the treatment, and I think if these are public health principles that we have lived under in the past, we should still be using them for this particular disease.

Mr. ROWLAND. Then what is the difference—why is there a difference—why is the medical community split?

Ms. ROCKETT. I can't always answer that and I think some people are concerned about people's civil rights and, of course, I am very concerned about the civil rights of the innocent victims right now. I don't want this spread to others unknowingly and I hope that the medical community will consider this.

I think that the demonstration that existed at the American Medical Association in Honolulu showed a great reversal of trend that had existed at prior meetings, when the medical profession were very concerned that it would infringe on people's civil rights.

Mr. ROWLAND. The AMA is going to testify later and I understand they are more inclined to put the responsibility on the States and have it—

Ms. ROCKETT. I am not speaking for them, but I just would cite what had happened, the reversal.

Mr. JONES. Mr. Rowland, may I answer that briefly? Ditto everything she said, but I want to point out what I said earlier, that 16

out of every 100 contacts were infected in two studies I spoke of. Go back and remember that if we had had a contact tracing program, those 16 people might not have become infected.

We are concerned about dollars and cents and we have compassion for the sick and the dying, but think about the dollars and cents and the compassion of those who could have been protected from being infected. It has been alluded to all day long. We have a massive problem now, but it pales to the comparison of what it will be if we allow those numbers to increase.

Mr. ROWLAND. Is this discrimination we hear about a legitimate concern?

Mr. JONES. It is. Sir, I am 25 or 26 years in clinical practice. I have been associated with the medical center that entire time and discrimination in sexually transmitted diseases just does not occur with any degree of notoriety. You don't see it.

Mr. ROWLAND. Not even with HIV?

Mr. JONES. I will have to let—I could answer on a small scale, but he has bigger numbers.

Mr. LISA. May I tell you that in my city, I think that the discrimination issue is a false issue. I think the people of the city of New York living with the tremendous stress, financially and in pain and in suffering that this epidemic has brought about to the city, are handling it with great honor. Think about it for a moment.

In the Ryan White situation, did you see a backlash in this Nation against blood donors that contaminated the blood supply? Did you see a backlash against blood bank officials who may have permitted the blood supply to—

Mr. ROWLAND. You are not answering my question. My question—

Mr. LISA [continuing]. Become contaminated? Of course there is no discrimination.

Mr. ROWLAND [continuing]. Is, is there a problem about discrimination? That is my question.

Mr. LISA. I don't believe there is legitimately. I think it is an issue that has been raised to confuse our ability to be able to deal with it.

Mr. ROWLAND. Who raised it? Why was it raised? Are your colleagues in medicine, then, not as—you are not a physician, though, are you?

Mr. LISA. No, I am not.

Mr. ROWLAND. Are those people in medicine, then, who will decide on that issue—are they—what about that?

Mr. JONES. Mr. Rowland, at the AMA meeting, there was not one dissenting vote in the House of Delegates when the arguments were finally delivered. It passed unanimously without vocal dissent.

Mr. ROWLAND. My time has expired.

Mr. WAXMAN. The gentleman's time has expired.

Mr. Nielson, do you need some more time?

Mr. NIELSON. I sure need it, I think. I can't raise quite the rumpus that Dr. Rowland does, who speaks from medical experience, but I was impressed by the statement two of you made that we should treat this as a public health project, just like we treat any other disease, rather than a civil rights issue.



Dr. Rowland is suggesting that maybe there is a tinge of civil rights along with the public health concern in this and there is probably some middle ground there and I would like to find that. I was particularly interested in Dr. Rockett's comment that the two bills are complimentary and there is some good from each bill that could be incorporated into something to help solve the problem.

Let me ask the thing that concerns me. In the previous panel, one of the men said that when they had confidentiality in the case of Oregon—Oregon and South Carolina are the two States he mentioned—when South Carolina went in one direction and Oregon went the opposite direction, in Oregon, which went to a confidentiality situation, the number who came forward increased. South Carolina, which abolished the confidentiality, decreased, and he used that as an example.

Now, Dr. Jones, you have used the States of Colorado and Arkansas to get just the opposite point of view.

Mr. JONES. I would like to say I would love to debate the gentleman who made that remark.

Mr. NIELSON. That is what I am giving you the opportunity to do. He used two States, you used two States—

Mr. JONES. He was referring to material that was produced in the literature more than 2 years ago, before there was an effective intervention and drugs for people who were HIV-infected and asymptomatic. Colorado was second in a survey of 22 States done about 2 years ago in continued volunteer testing, even though they were one of the first States to require reportability and contact tracing.

Mr. NIELSON. What you are saying is your two States are more recent.

Mr. JONES. I am saying—

Mr. NIELSON. Colorado and Arkansas might be more typical.

Mr. JONES. I am saying he is quoting literature that is more than 2 years old and I am giving you literature or facts that are current in current therapy.

Mr. NIELSON. I am not sure the time of the thing is relevant. I mean, I am just saying that—

Mr. JONES. Well, yes, it is because the attitudes change and the therapy is now available, although there were experts who said it was reasonable to do—to give AZT to asymptomatic patients 2 years ago. Now it is a peer-reviewed report in the world literature as of this month.

Mr. NIELSON. The chairman suggested that in other public health issues, we let the States decide. We don't have the Federal Government mandating how the States should handle it.

Mr. JONES. I am really not—

Mr. NIELSON. Do you agree with the chairman in that area?

Mr. JONES. I am not old enough to remember how syphilis began in terms of how it was handled, but I believe that in this situation, when we are talking about the Federal purse strings finally taking care of it and taking care of people, that it becomes a Federal reason to get involved, yes, sir.

Mr. NIELSON. My question—I think you are trying to lead me a little bit there—

Mr. JONES. I am sorry.

Mr. NIELSON. I am saying——

Mr. JONES. I get rather enthusiastic about my point of view, sir.

Mr. NIELSON. I am supposed to do that.

You have said, basically, that—or the chairman has made this comment—that in other health programs, such as leukemia and cancer and other things, each State handles it separately and particularly the public health issues like syphilis. Each State handles it itself without Federal directives.

Mr. JONES. We are talking about——

Mr. NIELSON. And so he is suggesting that maybe we shouldn't have Federal directives now. Do you agree with him or not?

Mr. JONES. If I may draw an analogy, when you talk about those other diseases——

Mr. NIELSON. Maybe I misquote you, Mr. Chairman. You may have——

Mr. JONES [continuing]. You are speaking something like a junior high basketball team versus a world championship basketball team. We are talking about big problems, sir. We are not talking about minor league diseases.

Mr. NIELSON. Those other disease are not exactly minor league, either.

Mr. JONES. I am saying, in terms of the numbers of people it impacts and the dollars and cents figures——

Mr. NIELSON. What I am trying to get you to say or to comment on——

Mr. JONES. Sir, I think we are together on this. I think we are probably not wording it correctly.

Mr. NIELSON. Not—no, you are in the wrong direction.

Mr. JONES. Okay. Convince me.

Mr. NIELSON. You have used two States as examples of saying that confidentiality or removing confidentiality, allowing referrals, allowing people to be notified, did not decrease the number of people coming in. You have used two States.

Mr. JONES. That is correct.

Mr. NIELSON. Do you think if the Federal Government did it that way, do you think the same thing would happen federally or do you think the Oregon/South Carolina example would happen?

Mr. JONES. I again say that the ball game has changed since 2 years ago when those statistics were reported. I am not sure that they would be repeated in today's world.

Mr. NIELSON. Mr. Lisa.

Mr. LISA. In New York, where we passed last year the strongest confidentiality statute, there was no increase in people coming in to be tested. I will tell you what will cause an increase, leadership provided by public officials like Chairman Waxman in encouraging early diagnosis and early treatment.

You see, up to now, we have had a public policy that has encouraged ignorance. We have encouraged the public to remain ignorant of their HIV status. Women do not have the right to know the HIV status of their husbands, their boyfriends, their whomever. Now, that is a terrible mistake.

Men don't have, as a matter of right, the right to know the HIV status of their spouses, their fiancées, their whomever. That is a terrible mistake.

We have to develop a public policy that encourages knowledge. We have to encourage people to want to know what their HIV status is and that is what is behind early diagnosis and early testing.

Mr. NIELSON. I still didn't get the answer to my question.

Mr. LISA. Confidentiality does not—confidentiality, at least in my opinion, and at least in the experience in my State, did not bring more people in to be tested. We have the strongest confidentiality law in the Nation and no more people came in in the one year it was in place than the year before.

Mr. NIELSON. If I may, Mr. Chairman, the State——

Mr. WAXMAN. No, the gentleman's time has expired.

The Chair recognizes himself for his second round.

Mr. Lisa, you think that people ought to know their HIV status. Do you think other people ought to know other people's HIV status?

Mr. LISA. No. This is what I do believe. I believe that people ought to know their HIV status so that they can take advantage and so do you, sir, because you did provide the leadership in the Nation——

Mr. WAXMAN. Just answer the question.

Mr. LISA. Yes. I believe people ought to know——

Mr. WAXMAN. Save the praise for another——

Mr. LISA. People ought to know—for two reasons. One, they——

Mr. WAXMAN. People ought to know their status.

Mr. LISA. That is correct.

Mr. WAXMAN. Should other people know your status?

Mr. LISA. I think my physician should so that he can best diagnose and best treat me——

Mr. WAXMAN. How about your wife?

Mr. LISA. Absolutely, and if I don't have the courage to tell her, my physician—it was a duty of my physician to tell her if I had syphilis. It should be his duty to tell if I have the most deadly virus known to man today.

Mr. WAXMAN. How about your constituents?

Mr. LISA. I don't think my constituents have a right to know my HIV status. That may come out, but certainly my wife does, and anyone that I may have—be sharing needles with or intimate sexual contacts with. Not people that I share doorknobs with and food——

Mr. WAXMAN. Okay, so people you have sexual contacts with.

Mr. LISA. That is correct.

Mr. WAXMAN. Now, should the doctor try to figure out who you are going to have sexual contact with?

Mr. LISA. Yes. He should ask me, and he should tell me—no, he should ask me because it is not done—I am glad you brought that up. It is not done with a rubber hose. Contact tracing, partner notification was a way of a beneficent——

Mr. WAXMAN. Excuse me, I am going to have to interrupt you because I only have a limited time and I want to ask a lot of questions and I want very brief answers.

Mr. LISA. My physician——

Mr. WAXMAN. Excuse me, Doctor, your physician should ask you and you should tell him.



Mr. LISA. That is correct.

Mr. WAXMAN. What if you don't tell him?

Mr. LISA. If I am not truthful, that is the end of it.

Mr. WAXMAN. Okay.

Dr. Jones, do you think we ought to have reporting and the contact tracing?

Mr. JONES. Yes.

Mr. WAXMAN. The reporting allows contact tracing. What if people don't come in? What if they think that there is going to be discrimination, and therefore, they don't come in to be tested?

Mr. JONES. It would be——

Mr. WAXMAN. Should we mandate it?

Mr. JONES. It would be very unfortunate. It would be their loss. It is still in the public's best interest to go ahead with this program.

Mr. WAXMAN. Should we mandate testing?

Mr. JONES. I can list several places of mandate testing. I wouldn't mandate the entire population, no.

Mr. WAXMAN. But you would mandate a lot of different——

Mr. JONES. There are many, and it is—I agree 100 percent with AMA policy on mandatory testing and I am sure you are familiar with it.

Mr. WAXMAN. Dr. Schwartz, do you think we ought to mandate the testing if people aren't going to come in?

Mr. SCHWARTZ. No, we shouldn't mandate it that way except in special situations. I have listed in my presentation that there are certain areas where we should have voluntary testing of everybody that comes through public facilities, hospitals, the various clinics. In that way, we may stem this horrible plague.

Might I interject, you asked these two gentlemen a question about would they tell if they had AIDS? Well, I don't have AIDS, but I did receive, about a year and a half ago, five blood transfusions of——

Mr. WAXMAN. Excuse me. I have to ask the questions and control what opportunities I am going to be able to ask questions in this area.

Mr. SCHWARTZ. Excuse me.

Mr. WAXMAN. We all want more people to be tested. There are people who believe that they are going to be discriminated against. Mr. Lisa doesn't believe it. Dr. Jones doesn't believe it, but the people who may well be likely to have AIDS do believe it. And they believe it because they have had experiences reported about people who have lost their insurance coverage, people who have lost their jobs, people who have been forced out of their homes because they have the HIV infection.

What are we going to do, Dr. Rockett, if we find that people are staying away, notwithstanding all of our encouragement to come in? Unless we make it mandatory, what are we going to do then?

Ms. ROCKETT. I think what has been said earlier today by the previous panel to encourage antidiscrimination measures, and this certainly——

Mr. WAXMAN. So you would want to encourage antidiscrimination measures?

Ms. ROCKETT. For example——



Mr. WAXMAN. To give assurances that they won't be——

Ms. ROCKETT [continuing]. In housing, employment, things like that. On the other hand, there is a great deal of effort being put into effect, as far as that is concerned. I would encourage strongly voluntary testing.

On the other hand, in high-risk settings, when that is not being complied with, I think we have to go ahead with mandatory testing and I will cite to you Patient Zero, who, when he was confronted——

Mr. WAXMAN. So you think under those circumstances, we would be able to catch a guy named Captain Zero.

Dr. Jones, what would you do with these patients once you have tested them and they are HIV-infected? We have——

Mr. JONES. Compassionately educate them about their disorder, offer them counseling, interview them or have them interviewed by appropriate epidemiologic surveyors for their contacts and contact——

Mr. WAXMAN. What if they won't tell you their contacts?

Mr. JONES. What if the index case does not tell?

Mr. WAXMAN. Yes.

Mr. JONES. Well, I have never dealt with the volume that he does and apparently they have some rule about it. I am not sure I would impose sanctions about it. I think when you—when a doctor has a good relationship with a patient, that material is not difficult to be forthcoming.

I want to say that you said that two of us—or at least I was included—don't recognize that there is discrimination. I recognize it, but it is a secondary concern of mine.

Mr. LISA. So do I. So do I, and it is a secondary concern because I think——

Mr. WAXMAN. It is a secondary concern to you, but it may be the major concern to someone who might stay away from getting tested——

Mr. JONES. But think about the volume of the uninformed contacts that are existing, and they——

Mr. WAXMAN. But they are all going to be uninformed of them if the person doesn't come in to be tested. That person is going to be uninformed, as well as the——

Mr. JONES. I hope you and I are not——

Mr. WAXMAN. My time has expired, but I appreciate what you have all had to say——

Mr. NIELSON. I ask unanimous consent——

Mr. WAXMAN. I object because we have another panel and they have been very patiently waiting.

Mr. DANNEMEYER. I join in his unanimous consent——

Mr. WAXMAN. The point I want to make to you is that the differences are there, not over the fundamental goals.

Just a clarification. There is no Federal law that requires States to have a reporting and confidentiality for syphilis or any other disease. Second, we haven't conquered syphilis. Syphilis has not been eradicated, even though every State does have mandatory reporting and contact tracing.

Mr. JONES. I would rather have syphilis——

Mr. WAXMAN [continuing]. But it is a tool, and we all want to use tools that we have available to us to the maximum extent possible. That, it seems to me, we all agree on.

Mr. JONES. Was a syphilis list ever published? You asked if an HIV list were published, would it interfere with anything. Was a syphilis list ever published in the press or in—so that general people could find out their their neighbor had syphilis?

Mr. NIELSON. Can you get questioned, Mr. Chairman?

Mr. WAXMAN. We don't allow that.

Mr. JONES. I withdraw my question, sir.

Mr. DANNEMEYER. Mr. Chairman, I just have a—not a question of the panel, but on the point of whether confidentiality encourages or discourages testing. I would like to ask unanimous consent to place into the record some data provided by the Colorado State Health Department that contrasts the rate per 100,000 of people that have been tested in States that have confidential, mixed, and anonymous testing.

Mr. WAXMAN. Without objection, the gentleman's submission will be included in the record and the record will also include any other comments on that point that may be submitted to us.

[The information follows:]

Population Based HIV Testing Rates for States With Confidential Mixed and Anonymous Testing Programs

State	Testing status	Population of 1980 census	Calendar year 1988 tests performed	Rate per 100,000—1980 census
Alaska .....	Confidential	401,851	<sup>1</sup> 6,477	1,611.8
Colorado .....	Confidential	2,889,964	17,318	599.2
Alabama .....	Confidential	3,893,888	17,170	440.9
South Carolina .....	Confidential	3,121,820	13,624	436.4
Minnesota .....	Confidential	4,075,970	8,150	200.0
Total .....		14,383,493	62,739	436.2
Missouri .....	Mixed	4,916,686	17,258	351.0
Oregon .....	Mixed	2,633,105	8,225	312.4
Arizona .....	Mixed	2,718,215	5,712	210.1
Total .....		10,268,006	31,195	303.8
California .....	Anonymous	23,667,902	112,977	477.3
Texas .....	Anonymous	14,229,191	<sup>2</sup> 36,000	253.0
New York .....	Anonymous	17,558,072	40,439	230.3
Illinois .....	Anonymous	11,426,518	9,721	85.1
Total .....		66,881,683	199,137	297.7

<sup>1</sup> 1989 data; 1988 data unavailable.

<sup>2</sup> Est.

Survey selection: Areas with high rates in 1987, areas with substantial AIDS morbidity, area who claim better testing with anonymous policies.

Mr. DANNEMEYER. I don't mean to make—extend it, but Colorado, with confidentiality testing, tested 599.2 out of every 100,000 persons in 1988; Oregon, with a hybrid system, tested 312.4 per 100,000; and California and New York, with an anonymous system tested 477.3 and 230.3 per 100,000 respectfully. The point is confidentiality in the law is not a discouragement to testing. In fact, the data suggests that more people are tested in States with confidential reporting.



Mr. WAXMAN. Thank you very much for your participation in this hearing.

Our last panel today is made up of representatives of national organizations, providers of health care services. Dr. John McGrath is representing the American Medical Association; Ms. Donna Richardson is representing the American Nurses Association and is also speaking on behalf of the National Organizations Responding to AIDS. Ms. Richardson chairs the Coalition Task Force on Health Care Services; and Dr. Frederick Rickles is representing the National Hemophilia Foundation.

We are pleased to welcome you to our hearing today. Your testimony will be in the record in full. We would like to ask each of you to limit your oral presentations to 5 minutes.

Dr. McGrath, we will start with you.

**STATEMENTS OF JOHN J. McGRATH, MEMBER, HOUSE OF DELEGATES, AMERICAN MEDICAL ASSOCIATION; DONNA RICHARDSON, COCHAIR, CARE TASK FORCE, NATIONAL ORGANIZATIONS RESPONDING TO AIDS; AND FREDERICK R. RICKLES, VICE PRESIDENT FOR MEDICAL AND SCIENTIFIC AFFAIRS, NATIONAL HEMOPHILIA FOUNDATION**

Mr. McGRATH. Thank you, Mr. Chairman, and members of the subcommittee.

I am Dr. McGrath. I am a physician in Washington, DC. I am a member of the American Medical Association's House of Delegates and I sit on the American Medical Association's Council on Legislation.

With me is Mr. Michael Zarski, of the Association's division of legislative activities.

First, Mr. Chairman, we commend you for your sustained leadership on this issue. We also commend every member of this subcommittee for the competent manner in which you have come to appreciate the responsible public health approach to this epidemic, which the AMA and others have advocated.

The AMA does not claim to have all of the answers. We have, however, diligently developed and promoted a comprehensive AIDS policy. This policy is updated and modified periodically as our knowledge of the disease improves and as scientific and social developments necessitate. We are gratified that many members of Congress have found our reports useful.

Turning to H.R. 4470, the AIDS Prevention Act of 1990, we find much which we now support and have supported in earlier legislation. Mr. Chairman, we are pleased that the bill acknowledges the importance of the confidentiality of HIV-related information. The AMA, however, would recommend going further. We advocate uniform protections at all levels of government of the identity of those with the HIV disease.

Title I of your bill, sir, also requires that States receiving grants provide a program of HIV contact tracing to the extent determined appropriate by the State's public health officer. Currently, the AMA strongly recommends that a system of contact tracing and partner notification be established in each community. Even as strong advocates of contact tracing, however, we must acknowledge

what public health authorities who administer these programs tell us, no one model of partner notification will be effective in every location. Thus, it is critical to allow for discretion of the State.

As you know, effective partner notification and contact tracing programs are expensive. Legislation to encourage these programs should be accompanied by Federal funding.

Title II of the act addresses the financing of care for HIV-infected individuals. As mentioned in our submitted statement, the AMA Board of Trustees is meeting this week in Chicago. They have considered your previous bill, H.R. 4080, Mr. Chairman, which is now title II of this bill, and I am pleased to say that they have approved support of that bill which is incorporated as title II. That was done yesterday.

Mr. Chairman, we would like next to direct our comments to H.R. 3102, the Public Health Responses to the AIDS Act. We commend the sponsor, Congressman Dannemeyer, for his continued efforts to seek feedback and reaction from the American Medical Association. We have stated already our support for reportability of seropositive patients for the purposes of contact tracing. We are pleased that H.R. 3102, like Representative Waxman's bill, allows the State Public Health officer to determine the appropriate extent of contact tracing.

The AMA also supports mandatory testing of prisoners. We believe, however, more discretion needs to be left in the hands of prison authorities than H.R. 3102 currently allows.

The AMA supports State sanctions for an infected individual who knowingly and willfully risks infecting an unsuspecting person when that person subsequently discovers the risk and makes a complaint.

In other respects, however, H.R. 3102 does not reserve appropriate discretion and flexibility for the States. We do not support a Federal requirement that States with one-tenth of 1 percent infection rate offer HIV testing to those applying for hospital licenses nor for hospital inpatients between 15 and 50 years old, those who will undergo surgery or those having their blood tested for any other purpose.

The AMA does not support a Federal requirement that in every State, HIV be considered a sexually transmitted disease. We are unable to determine the impact of such a blanket requirement and we recommend that each State should determine whether to include HIV as a sexually transmitted disease only after a full analysis of the consequences of such an action in light of existing State law.

The AMA also recommends that your Federal—that you include Federal confidentiality standards. We would be pleased to provide specific model legislation incorporation our recommended standards and exceptions for confidentiality.

Mr. Chairman, we thank you for this opportunity to appear. We are appreciative of the sincere interest which you have shown to our views and we look forward to your questions later, sir.

[The prepared statement of Mr. McGrath follows.]



STATEMENT OF THE AMERICAN MEDICAL ASSOCIATION, PRESENTED BY JOHN J. McGRATH, RE: FINANCING AIDS HEALTH CARE

Mr. Chairman and Members of the Subcommittee, my name is John J. McGrath, M.D. and I am a physician in the practice of psychiatry in Washington, D.C. I also am a Member of the American Medical Association's House of Delegates and I sit on the AMA's Council on Legislation. With me is Michael Zarski of the Association's Division of Legislative Activities.

Because the AMA's Board of Trustees is meeting now in Chicago, the Board Chairman has asked me to present the Association's views on the Human Immunodeficiency Virus [HIV] epidemic and the legislative proposals addressing these issues.

First, Mr. Chairman, we must commend you for your sustained leadership on this issue. We also commend every member of this Subcommittee for the competent manner in which you have come to appreciate the responsible public health approach to this epidemic which the AMA and others have advocated. It was a mere few years ago that a witness at a hearing before this Subcommittee advocated placing HIV-infected individuals in quarantine on a remote former leper colony in Hawaii. This Subcommittee, and the Congress as a whole, has rejected extreme measures which appealed to those with the most fear and the least understanding of AIDS.

Of course, it seems to be easier to agree on what would not be an effective or appropriate response to the HIV epidemic than to agree on what steps should be taken by the Federal government.

The AMA can't claim to have all the answers. We have, however, diligently developed and promoted a comprehensive AIDS policy. This policy is updated and modified periodically as our knowledge of the disease improves and as scientific and social developments necessitate. We are gratified that many Members of Congress have found it useful to refer to the Association's AIDS policy in determining how to vote on a bill or amendment.

Turning to H.R. 4470, the "AIDS Prevention Act of 1990," we find much which we would support and which we have supported in earlier legislation. The grant program created by Title I would provide essential funding for preventive health services such as HIV antibody testing and counseling. In addition, grants could be used to provide other HIV-related diagnostic tests and therapeutic measures. We note in particular our support for a reliable source of federal funding of therapeutic measures. The absence of such a source of funding was demonstrated last year when "temporary" federal funding for the drug AZT almost terminated upon more than one occasion.

The AMA also supports the provision which would allocate grant funds based on the number of and increase in HIV infections in 1992 and subsequent years rather than on reported AIDS cases. We all understand that the disease is a continuum from the HIV infection to the symptomatic stage known as AIDS. Preventive health services and therapies which promise to prolong the asymptomatic stage of the infection must be targeted to those areas where infection is on the rise—it is less logical and less effective to rely on data regarding the last stages of the disease.

The recognition of the potential adverse impact of HIV-infection on rural areas is another aspect of H.R. 4470 which we support. Although the overall numbers may be lower than those of more populated metropolitan areas, a rural health care delivery system may be struck with disaster as a consequence of the HIV epidemic.

Mr. Chairman, we are gratified that the bill acknowledges the importance of the confidentiality of HIV-related information by requiring assurance from grantees that applicable confidentiality law will be followed. The ANA, however, would recommend going further. We advocate uniform protections, at all levels of government, of the identity of those with HIV disease except where public health requires otherwise. We have, as you know, previously supported federal legislation with confidentiality standards included and we have prepared and advocated the adoption of our own model state bill on confidentiality.

The counseling requirements of H.R. 4470 are suitable and consistent with the advice we give to physicians regarding the scope of the pre- and post-test counseling. It is absolutely essential that appropriate counseling accompany all HIV testing. Even the U.S. military testing program, which administers millions of tests, adheres to this important public health principle.

Title I of H.R. 4470 also requires that states receiving grants provide a program of HIV contact tracing to the extent appropriate as determined by the state's public health officer. The AMA supports this provision. The Association has since our earliest AIDS policy report supported contact tracing programs to warn unsuspecting

partners of HIV infected individuals. Currently, the AMA strongly recommends that a system for contact tracing and partner notification for unsuspecting sexual or needle-sharing partners who might have been HIV infected should be established in each community. This recommendation includes programs which rely on the reporting of HIV seropositive patients to the departments of health for the purposes of contact tracing. Even as strong advocates of contact tracing, however, we must acknowledge what the public health authorities who administer the programs tell us—that no one model of partner notification will be effective in every local population. Thus, it is crucial that any federal program encouraging contact tracing include a provision, such as in H.R. 4470, allowing for the exercise of discretion by the state public health officer.

Moreover, effective partner notification and contact tracing programs are expensive. Legislation to encourage these programs should include federal funding. Local public health programs should not be forced to choose between funding contact tracing programs and funding other beneficial public health programs such as children's immunizations.

Title II and Title III of the AIDS Prevention Act involve the financing of care for HIV-infected individuals. The bill would give states the option of providing Medicaid coverage for HIV-related health care services for HIV-infected individuals who have not yet progressed to AIDS. It would also increase Medicaid payments for hospitals which treat a disproportionate share of AIDS patients and authorize states to pay premiums for private health insurance.

Under Title III, federal assistance would be provided through a grant program designed to finance state and local development of effective cost efficient systems for delivering AIDS-related health care services.

These titles have been modeled after legislation which was introduced earlier this year. The AMA's Board of Trustees is reviewing these bills at this moment. Therefore, we must reserve specific comment. In general, however, existing Association policy recommends financing HIV care through private insurance and existing public programs, including enhancement of Medicaid in particular.

The remaining major Titles of H.R. 4470 concerning emergency response employees and the provision of drugs such as AZT are consistent with legislative proposals which the AMA has supported in the past.

Mr. Chairman, we would like to next direct our comments to H.R. 3102, the "Public Health Responses to AIDS Act." We commend the sponsor, Mr. Danne-meyer, for his continued efforts to seek feedback and reaction from the AMA and other elements of organized medicine regarding his proposals. After reviewing both H.R. 4470 and H.R. 3102 we are optimistic that an acceptable bipartisan measure will soon emerge from this Subcommittee.

Regarding the specifics of H.R. 3102—we have stated already our support for reportability of seropositive patients for the purposes of contact tracing. We are pleased that in H.R. 3102, like Representative Waxman's bill, allows the state public health officer to determine the appropriate extent of contact tracing.

In other respects, however, H.R. 3102 does not reserve appropriate discretion and flexibility for the states. We do not support a requirement that states with 0.1 percent infection rates offer HIV testing to those applying for marriage licenses; hospital inpatients between 15 and 50 years old; those who will undergo surgery; or those having their blood tested for any other purpose.

While the AMA supports mandatory testing of prisoners, we believe more discretion needs to be left in the hands of prison authorities than H.R. 3102 currently allows. For example, testing for HIV antibodies before and after each leave or furlough from prison, however brief, is excessive. Such closely spaced testing is not likely to yield useful information even if infection occurs, because antibodies do not develop so rapidly. Regarding other provisions of the bill:

(1) The AMA supports state sanctions for an infected individual who knowingly and willfully risks infecting an unsuspecting person when that person subsequently discovers his/her risk and makes a complaint to the authorities. Preemptive sanctions are not being endorsed by this recommendation.

(2) The AMA does not support a federal requirement that in every state, HIV be considered a "sexually transmitted disease" for purposes of any state laws. We simply are unable to determine the impact of such a blanket requirement and are concerned over the potential unintended consequences of such a sweeping requirement. Each state should determine whether to include HIV as a "sexually transmitted disease" only after a full analysis of the consequences of such an action in light of the existing state law which would be affected.



The AMA also recommends that you include federal confidentiality standards. We would be pleased to provide specific model legislation incorporating our recommended standards and exceptions for confidentiality.

Mr. Chairman, we again thank you for this opportunity to appear before you and appreciate the sincere interest with which our Association's views and positions are received. As a consequence of the hard work and many hearings conducted by this Subcommittee, it appears that the Members are close to agreement in many respects. We therefore urge the Subcommittee to arrive at acceptable legislation which will address the issues of health care financing for AIDS and meet the pressing needs which exist today.

Mr. WAXMAN. Thank you very much, Dr. McGrath.

Ms. Richardson.

#### STATEMENT OF DONNA RICHARDSON

Ms. RICHARDSON. Good afternoon. My name is Donna Richardson. I am director of congressional and agency relations for the American Nurses Association, ANA, and the cochair of the Care Task Force of the National Organizations Responding to AIDS, NORA.

NORA was established in 1987 as a Washington-based coalition of health and social service professional associations, consumer and advocacy agencies and diverse other interest groups addressing HIV-related issues throughout the country. The coalition currently has 150 national organizations affiliated.

Thank you for the opportunity to speak today about the merits of H.R. 4470, the AIDS Prevention Act of 1990. Embodied in this legislative proposal are some of the most needed initiatives and progressive health care ideas required for the HIV epidemic and the Nation's health care delivery system in general.

Together with the components of its companion bill, S. 2240, our Nation has its most substantive health policy proposal yet with regard to the HIV epidemic. It is enthusiastically welcomed and urgently needed.

The NORA coalition has placed a high priority on care issues during the 101st Congress. Ensuring the delivery and financing of health care for people with HIV disease is the most serious AIDS-related policy challenge facing the Congress and the Nation. Over the past 9 years of the HIV epidemic and, in spite of the leadership efforts of this subcommittee, the Federal response has been characterized as slow, callous and actively nonresponsive, especially in the area of care.

An analysis of the past Federal budgets for AIDS shows that funds dedicated to care and the discretionary spending of the Public Health Service even now only rise to just over 5 percent.

Our Nation's current system of both private and public health insurance has demonstrated serious flaws. The solutions are clearly complex, but H.R. 4470 provides the initial components of both short-term relief and a long-term solution.

A potential new case load over this year and the next ranges from 108,000 to 128,000 cases. Increasing case loads in rural areas were reported just this week to the National Commission on AIDS. We must address both the care-related needs of those currently sick and provide access to promising early interventions for those who are HIV-infected, of which CDC estimates more than 500,000 could benefit.

The Nation's commitment to research in the AIDS crisis is to be applauded. The result of the billion dollar investment in identifying the virus and producing retardant therapeutics is a major triumph, but it is meaningless if individuals have no ability to access these therapeutics and the required care. Adequate numbers of nurses and doctors are necessary to provide access.

At this time, I would like to take the opportunity to address a point mentioned by Dr. Rockett. The American Nurses Association, the Association of Operating Room Nurses, the American Association of Critical Care Nurses and the Association of Practitioners in Infection Control, along with OSHA and the CDC stress to all health care workers that universal precaution is to be used with all exposures to blood and body fluids because testing does not guarantee knowledge of HIV infection.

I am also pleased and proud as a nurse to say that although nurses have the same fears and concerns that the lay public has about HIV infection, more nurses are working today than ever before. The data also shows us that in the last year, there has been a 6 percent increase in nursing school enrollment. We also know that nurses are on waiting lists to work in designated AIDS units.

The creation of a discretionary program to build a coordinated structure of testing, counseling and early intervention is a cutting edge proposal in AIDS care delivery. Since a drug is available, as the Secretary of HHS has reported, that slows the progression of HIV disease, we believe the Federal Government is compelled to respond with a proposal to deliver such care and ensure access to such treatments.

To date, the issue of HIV testing has been controversial. In the past, most public health experts warned that without effective treatments and protection from discrimination and inappropriate disclosure, testing had little to offer by way of health care provision and treatment. Today, that analysis has clearly evolved, but not necessarily in as dramatic a way as some would like us to believe.

AZT is available, but not necessarily accessible. Commendably, hostile acts of hatred and discrimination against the HIV-infected and those who care for them have abated, but there is still no civil rights protection currently provided at the Federal level for the HIV-infected.

For the first time, the Federal response to AIDS will begin to deal with creating and funding a coordinated and comprehensive system of prevention and health care delivery. When this system is in place, and not before, the treatments available to the HIV-infected will legitimize testing as an appropriate public health tool in both primary and secondary prevention.

The bill's intention to maintain confidentiality, informed consent and anonymous testing policies—we would like to endorse the State's jurisdiction over public health policies regarding communicable diseases.

We commend the chairman and the committee for addressing this issue.

Thank you.

[Testimony resumes on p. 345.]

[The prepared statement of Ms. Richardson follows:]



## STATEMENT OF NATIONAL ORGANIZATIONS RESPONDING TO AIDS

Good morning, my name is Donna Richardson, I am Director of Congressional and Agency Relations for the American Nurses Association and the Co-chair of the CARE Task Force of the National Organizations Responding to AIDS (NORA). NORA was established in 1987 as a Washington based coalition of health and social service professional associations, consumer and advocacy agencies, and diverse other interest groups, addressing HIV-related issues throughout the country. The coalition currently has 150 national organizations affiliated.

I am pleased to speak today about the merits of H.R. 4470, The AIDS Prevention Act of 1990. Embodied in this legislative proposal are some of the most needed initiatives and progressive health care ideas required for the HIV epidemic and the nation's health care delivery system in general. Taken together with the components of its companion bill S. 2240, our nation has its most substantive health policy proposal yet with regard to the HIV epidemic. It is enthusiastically welcomed and urgently needed.

The NORA coalition has chosen to place a high priority on care issues during the 101st Congress. Ensuring the delivery and financing of health care for people with HIV disease is the most serious AIDS-related policy challenge facing the Congress and the nation. Over the past nine years of the HIV epidemic -- and in spite of the efforts of this Subcommittee -- the federal response has been characterized as slow, callous and actively non-responsive. Nowhere is this more clearly demonstrated than in the area of care. In an analysis of the federal budgets for AIDS over the past eight fiscal years, the amount of funds dedicated to care in the discretionary spending of the Public Health Services even now rises to just over 5%. Our nation's current system of both private and public health insurance has demonstrated serious flaws in a system that already leaves more than 35 million Americans uninsured and therefore without access to quality health care. The solutions are clearly complex but H.R. 4470 provides the initial components of both short term relief and a long term solution.

As the second decade of the HIV epidemic begins, the country faces a potential new caseload over this year and next ranging from 108,000 to 128,000 cases. Increasing caseloads in rural areas were reported just this week to the National Commission on AIDS. Federal, state and local jurisdictions must address both the pressing and diverse care-related needs of those currently sick, and provide access to promising early interventions for those who are HIV infected. The cumulative AIDS caseload to date is over 120,000; the estimated number of HIV infected is approximately one million. The number of estimated infected people who could benefit from the early interventions currently recommended is estimated by CDC at more than 500,000.

The nation's commitment to research in the AIDS crisis is to be applauded. The result of the billion dollar investment in finding the virus and producing therapeutics that appear to slow its

progression is a major triumph of the last decade. However, all of this is meaningless if individuals have no ability to access these therapeutics and the required health care necessary to accompany them.

H.R. 4470 begins on two important fronts to deal with the issue of access to early intervention.

First, the authority to create a discretionary program to build a coordinated structure of testing, counselling and early intervention is a cutting edge proposal in AIDS care delivery. If a drug is available, as the Secretary of Health and Human Services has reported, that slows the progression of HIV related illness, we believe the federal government is compelled to respond with a proposal to deliver such care and assure access to such treatments. To date, the issue of HIV testing has been controversial. The arguments about who should be tested, how they should be tested, the complement of counselling that should accompany the testing,



and who should be informed about the results of HIV tests have been spirited and long. In the past, most public health experts warned that without effective treatments and protection from discrimination and inappropriate disclosure, testing had little to offer by way of health care provision and treatment. Today that analysis is clearly changed, but not necessarily in as dramatic a way as some would lead us to believe. AZT is available, but not necessarily accessible. Commendably, hostile acts of hatred and discrimination have abated, but there is still no civil rights protection currently provided at the federal level for the HIV infected.

The importance of H.R. 4470 is that for the first time the federal response to AIDS begins to deal with the substance of creating and funding a coordinated and comprehensive system of prevention and health care delivery. When this system is in place, and not before, the treatments available to the HIV infected will begin to legitimize testing as an appropriate public health tool in both

primary and secondary prevention.

The bill's intention to maintain confidentiality, informed consent, and anonymous testing consistent with applicable state laws is an essential component of continuing confidence in -- and participation in -- existing testing programs. However, issues related to contact tracing continue to be problematic from both a public health and regulatory perspective. The current draft of H.R. 4470 calls for -- as a condition for receipt of funds -- contact tracing programs in all states, but leaves specific discretion for program design and extent in the hands of the state public health officer. This is consistent with CDC's existing requirements that all state public health officials have in place contact tracing programs responsive to local needs and therefore does not require federal statutory consideration. It is well understood that the cost and labor intensiveness of contract tracing activities require that they be put in place in a targeted manner and reflect local needs and demographics that vary widely.

It is our understanding that the intent of the bill is to have the Secretary assure that programs are in place but not to exercise federal control over what obviously must be a locally determinable process.

NORA's Care Task Force supports the bill's establishment of a responsive system of testing, counselling and early intervention as an essential step forward in prevention and health care infrastructure development. The Medicaid eligibility reform proposal is effective because it establishes access to an appropriate steady reimbursement stream which will act to institutionalize the service delivery system within communities.

The current "Catch 22" of the Medicaid system that disallows persons who are poor from access to services because they are not acutely ill with AIDS but rather HIV-infected and at risk of acute illness does not make moral or financial sense. Our current system is biased toward providing care at the most expensive , most acute

level. Congress Waxman's proposal will allow less expensive alternatives to be utilized at an earlier level, hopefully postponing the onset of serious illness. Access to a complement of outpatient services proposed in the legislation will significantly assist those health care facilities that are collapsing under an enormous increase in AIDS cases. The American Nurses Association has long been an advocate for the expansion of outpatient services reimbursed by Medicaid. The National Association of Public Hospitals recently reported that an average AIDS admission in the United States cost a hospital \$2,500 in uncompensated or under reimbursed care. Through your Medicaid coverage expansion for asymptomatic individuals, we can anticipate people staying healthier longer and out of more expensive hospital and acute care settings.

It is most unfortunate that the impact of AIDS has already caused a disaster in a number of our nation's largest cities and urban counties. The emergency relief proposed in H.R. 4470 is urgently



needed in those cities that have been at the epicenter of the AIDS crisis. The NORA Care Task Force has spent the better part of this year working with the Chairman and members of the Committee as well as your colleagues in the Senate on this urgent and necessary proposal. We have all seen and recall the decisive actions by the Congress in relationship to Hurricane Hugo and the San Francisco earthquake. The same spirit of assistance and compassion is called for in the AIDS epidemic.

Reports from San Francisco tell us that that city's now famous model for AIDS community care is about to collapse. Private resources are not capable of providing the necessary funds to pay for the continuation of prevention efforts and provision of health care. A recent study showed that the cost of an AIDS patient in San Francisco was half the cost of caring for a similar patient in Los Angeles due to the community based model established by that community. Emergency assistance will assist in keeping the model operating and the long term costs of this epidemic down.

The disaster of AIDS is not only affecting the care and treatment of people with AIDS, it is straining all of the existing public health and social services systems in our country. Members of the National Commission on AIDS described the "AIDS Calcutta" they witnessed in the New York City Hospital System. Hospital corridors were jammed with patients who could not access beds because other patients had yet to be discharged due to a lack of out of hospital care. This situation jeopardizes the health access of all citizens. An inadequate social service system has finally reached its limits with the AIDS epidemic. How is the foster care system supposed to deal with more than 2,000 cases of pediatric AIDS and the large number of children whose parents have died from this disease?

The emergency assistance proposed in H.R. 4470 does not solve these problems but it does provide support necessary to shore up a strained system until such time as more systemic solutions are

found and implemented.

Finally, Mr. Chairman, the NORA coalition applauds your efforts at continuing the demonstration projects that have assisted communities in coping with the HIV crisis. In your home city of Los Angeles these funds have provided for a cost effective and coordinated care system that may serve as a model for other cities. In particular, a consortia of adolescent and youth services providing HIV prevention and care has been remarkable in its success and applauded by many throughout the nation. The authority to continue the State subsidies for AIDS therapeutic drugs will allow a literal lifeline for thousands to remain in place. However, we consider the current proposal to be far too small to adequately meet the growing caseload need.

AIDS is a difficult and complex issue from every purview. The care issues addressed here today are very difficult but represent a response to an inadequate health care system and the lack of a

cohesive health care policy. The NORA coalition pledges its support for reform in the nation's health care system and believes strongly that until such reforms are enacted, AIDS and other health care challenges will remind us, in a tragic way, that our job has not been done. Until that day, people will remain in dire need. The provisions of this bill begin to build a system of support for services and reform some of the most serious obstacles to care currently exacerbating the AIDS epidemic.

Thank you.



Mr. WAXMAN. Thank you very much, Ms. Richardson.  
Mr. Rickles.

#### STATEMENT OF FREDERICK R. RICKLES

Mr. RICKLES. Thank you. My name is Frederick R. Rickles and I am a physician, professor of medicine, Director of the Comprehensive Hemophilia Treatment Center at the University of Connecticut Health Center in Farmington, CT.

I am here today as Vice President for Medical and Scientific Affairs of the National Hemophilia Foundation and representing the 10,000 to 20,000 individuals, like Ryan White, for example, who were infected inadvertently with the Human Immunodeficiency Virus by their exposure to transfused blood products and factor concentrates required for the treatment of their hemorrhagic disorders.

NHF is a voluntary health agency working to improve the health and welfare of the some 20,000 persons with hemophilia, von Willebrand's Disease and other clotting factor deficiencies in the United States.

I would like to define for you at this time what comprehensive hemophilia treatment centers are and give you some notion, I hope, of the benefit that the community of patients with hemophilia have derived from the very wise decision of Congress in 1976 to fund these comprehensive hemophilia centers.

In short, and in brief, comprehensive hemophilia treatment centers are exactly what you are proposing for the treatment of AIDS embodied already for the treatment of hemophilia. They provide multidisciplinary care. They provide outreach activities and they allow patients with hemorrhagic disease to have access to virtually all health care and psychosocial services in a setting that provides confidence and confidentiality.

Hemophilia treatment centers were in place when the AIDS epidemic hit and thank God they were because at least they were able to respond in a well-organized manner and had excellent relationships with their patients, such that they were able to respond well to the needs initially demonstrated by the epidemic.

Some measure of success has been achieved by virtue of this complex network that is regionalized and present throughout the United States of comprehensive care centers. Approximately 50 percent of patients in attendance at these centers have now been voluntarily counseled regarding risk reduction behavior, have been tested, and the hemophilia treatment centers have been quite effective in documenting risk behavior changes amongst their population and participating in voluntary partner notification, programs with documented success rates.

The hemophilia treatment centers may be one of the more effective models for the delivery of preventive health services and have been referred to as such by both the President's Commission on AIDS and in the Omnibus Budget Reconciliation Act of 1981.

But I am afraid to tell you today the hemophilia treatment centers are overtaxed. They responded well to the epidemic initially, but with a 100 percent increase in patient visits over the past 3 years, a 200 percent increase in HIV-related visits to the hemophil-

ia treatment centers and a 300 percent increase in hospital admissions for HIV-related problems amongst patients with hemophilia, the hemophilia treatment centers can no longer tolerate the burden that is upon them.

I think we may compare the hemophilia treatment centers to an aspect of the present bill that deals with innercity health facilities. Both are dealing with a relative disproportionate number of patients with HIV infection. Overall, approximately 60 percent of our patients are infected with HIV. Therefore, we enthusiastically support both H.R. 4470 and H.R. 4080 as bills which provide many important services, but we would like to recommend one major addition.

We want to work with you to strengthen H.R. 4470 to include hemophilia treatment centers under virtually all provisions of the bill. Hemophilia treatment centers are the places that patients with hemophilia will get their care. They go there now; we want to serve more of the population. It makes sense, therefore, to use an existing, effective, multidisciplinary health care system which has already proven itself to be capable of reaching more and more people, and accomplishing the goals of the bill, to extend the provisions of this bill to more people with HIV infection.

Therefore, we believe that all grant mechanisms authorized in H.R. 4470 should ensure that the comprehensive hemophilia treatment center network be the primary mode for the delivery of preventive health services for persons with hemophilia, their families and partners, which they currently serve.

In regard to H.R. 4080, we support this approach for financing through Medicaid many of the provisions that are necessary for our patients. Clearly, many of our patients will benefit since they may require up to \$150,000 each per year to obtain virus-free factor 8 concentrates or factor 9 concentrates, the treatment they need for their hemophilia.

In addition, they will benefit from obtaining AZT and other HIV-related antiinfectious agents, also expensive drugs.

Thank you very much, and we appreciate the enlightenment of this committee.

[The prepared statement of Mr. Rickles follows:]

STATEMENT OF FREDERICK R. RICKLES, M.D., VICE PRESIDENT, MEDICAL AND SCIENTIFIC AFFAIRS, NATIONAL HEMOPHILIA FOUNDATION

My name is Frederick R. Rickles, M.D., professor of medicine and director of the Comprehensive Hemophilia Treatment Center at the University of Connecticut Health Center in Farmington. I am here today as Vice President for Medical and Scientific Affairs of the National Hemophilia Foundation [NHF]. NHF is a voluntary health agency working to improve the health and welfare of the 20,000 persons with hemophilia, von Willebrand's Disease and other clotting factor deficiencies in the United States.

I have been involved in the care of patients with hemophilia since 1960, when, as a student, I began to work in a medical research laboratory on human clotting problems and the defects responsible for bleeding disorders like hemophilia. At that time patients with hemophilia rarely lived beyond middle age. Most of our adult patients were confined to wheelchairs due to joint damage caused by repeated bleeding episodes. All that changed through the discovery of methods for concentrating the missing clotting factor responsible for two major forms of hemophilia, combined with the development and expansion of a regionalized network of comprehensive hemophilia treatment centers [HTC]. The establishment of the treatment centers was made possible by Congress in 1976—the first year of federal support for the Compre-



hensive Hemophilia Diagnosis and Treatment Centers Program (P.L. 94-63). Thanks to your help, over 9,500 persons with hemophilia (nearly 50 percent of the total hemophilia population) are now served by these 25 centers and 120 affiliates which provide multidisciplinary services including psychosocial, and vocational counseling, in addition to medical, dental and orthopedic care. The impact of this program, which is funded through the Maternal and Child Health setaside, has been dramatic. Congress' investment in comprehensive care which promotes home therapy has paid off. Over a ten-year period, disability was reduced with a 73 percent decrease in the average days per year lost from work or school; overall cost of care per patient per year declined 74 percent; the average days per year spent as an inpatient went down 83 percent; and unemployment was reduced 74 percent.

It has been a remarkable experience for me to participate in this effort from a time when patients were absolutely dependent on the health care system to this recent time of greater independence and self-achievement. My patients now include the past captain of the, Cornell swimming team, a young man who competes in long distance bike races, a master of Tai-Kwon-Do, and many others who are physically fit—the beneficiaries of the new forms of blood plasma products and comprehensive care. I have been delighted with all the individual success stories as our patients were able to achieve independent, full and productive lives.

I am sure you can appreciate the intense level of frustration that I felt, when overnight, this success story became a nightmare. Half of the total hemophilia population became infected with Human Immunodeficiency Virus [HIV] and one in fourteen has now been diagnosed with AIDS. Most ironic of all, it was the very blood products that liberated this population from the constraints of their chronic bleeding disorder, that was the source of this tragedy. Fortunately, it appears that as a result of new virus inactivation technologies applied to the blood products used by people with hemophilia, it is not likely that HIV negative patients will be exposed to the AIDS virus any longer as a result of their treatment. However, the damage has already been done to the 10,000 to 12,000 people with hemophilia who are HIV positive. The impact of AIDS on people with hemophilia, their families and health professionals has been tragic. This Subcommittee's help in the past has made a difference, but as the seriousness of AIDS, and the advancement of the disease in the hemophilia community has expanded, so have our needs.

The HTC program was originally established by Congress in 1976 to create a regionalized network providing comprehensive care services. The HTC program soon became a success model for the management of other chronic diseases. In the 1981 Omnibus Budget Reconciliation Act, the HTC program was referred to as the "biomedical success story of the decade."

With the advent of AIDS, the HTC program became the framework through which AIDS treatment, risk-reduction and psychosocial support services were provided to persons with hemophilia and their families. This was essential when you consider that one out of every 14 people with hemophilia has contracted AIDS and over 60 percent of the entire hemophilia community is HIV-positive.

The effectiveness of the HTC program in addressing the AIDS epidemic was cited in the June 1988 report of the President's Commission on AIDS in which there was a recommendation "to extend the network of centers" to the "hemophilia population not now being served." In December of 1989, the National AIDS Commission, in its first report, recommended "the creation of regional centers or networks of care, perhaps using the already existing regionalized hemophilia treatment program as a model." Also in 1989, the Surgeon General's workshop on pediatric AIDS recommended that "the hemophilia centers should receive additional funding to meet the increased need for services for HIV-infected children with hemophilia."

Without this comprehensive HTC network it would not be possible to deliver the comprehensive array of AIDS-related services needed by the hemophilia community today. However, the HTC "model" is in serious disrepair due to the enormous toll the AIDS epidemic has had on the hemophilia community. The HTC network currently has adequate resources to serve about one-third of the hemophilia population, partially serve another one-third, and the remaining one-third are unserved. The HTC network is in dire need of \$4 to \$5 million in fiscal year 1991 to provide the additional support needed to recruit nurse coordinators and social workers in urban and rural areas currently under- or unserved.

Hemophilia Treatment Centers are struggling with the demand that HIV infection and AIDS have placed upon them: costs of care and factor have risen dramatically; demands upon staff time by more and sicker patients have escalated markedly; and new staff skills and knowledge are required for providing HIV-related services.

It is estimated that between 15 percent and 20 percent of sexual partners of people with hemophilia have been exposed to HIV. For this reason, in January 1989, OMCH and CDC established a national goal for the hemophilia community to "prevent new cases of HIV infection in the sexual partners and offspring of persons with hemophilia".

Supplemental funding through OMCH, in cooperation with CDC, is provided to federally funded HTC's and to NHF for the purpose of preventing sexual and perinatal transmission of HIV. Substantial emphasis is placed on outreach directed at underserved and underserved populations, especially those of minority racial/ethnic groups and spouses and sexual partners of at-risk or HIV-infected persons with hemophilia. HTC's have used the HIV/AIDS grant money to build and expand their comprehensive care program to include HIV-related education, counseling, outreach and clinical services. NHF has developed a Women's Outreach Network and has created a National Hemophilia/AIDS Information and Resources Center.

Funding has also been allocated to evaluation activities to monitor the progress of the National Risk-Reduction Program. OMCH has done an excellent job in coordinating that program; some of the preliminary data gathered through the grant application indicate the following trends: The number of patient seen by HTC's has risen, with some centers reporting increases of over 100 percent in the past few years; 88 percent of people with hemophilia enrolled in HTC's are receiving comprehensive care and risk-reduction services; more than 50 percent of these individuals have been HIV tested; HIV-related visits have increased 200 percent, with hospital admissions up to 300 percent.

Mr. Chairman, the NHF supports the purposes of your bill to establish a nationwide program of providing preventive health services for AIDS.

The approach taken in H.R. 4470 is comprehensive in scope which NHF believes to be critical to achieving effective risk reduction. The Bill provides for confidentiality and informed consent protection for pre- and post-test counseling services, which are prerequisite to encouraging individuals voluntarily to seek preventive health services.

The maintenance of confidentiality is a matter of utmost importance to patients with hemophilia, their families and partners, as well as the hemophilia treatment team for several reasons. Inadvertent release of test results is associated with risk of discrimination, exclusion, and expulsion for individuals with hemophilia, their family members and partners. The serious consequences of such disclosure could result in loss of insurability, housing, employment and community life for hemophilia patients and families. Failure to protect confidentiality to the greatest extent possible could result in a patient's decision not to be tested or in a treater's recommendation not to test for fear of the potential negative outcomes of such a decision. Our community is already confronted with situations where individuals with hemophilia are not testing due to fear of breach of confidentiality and resulting discrimination. Because of these serious concerns some treaters have suggested that individuals with hemophilia not be tested, but simply consider themselves antibody positive and exercise the necessary precautions to reduce the risk of transmission to sexual partners.

H.R. 4470 seeks to alleviate this situation by requiring confidentiality and informed consent and establishing a nationwide plan of action for preventive health services with respect to AIDS. It does so by providing for maximum use of existing health care clinics and centers including hemophilia treatment centers, which individuals are familiar and comfortable with in treating their health problems. While we agree with this approach, we feel it is paramount that: (1) All grant mechanisms authorized in H.R. 4470 ensure that the comprehensive hemophilia treatment centers network be the primary mode for the delivery of preventive health services for persons with hemophilia, their families and partners; and (2) the hemophilia community has direct representation on the local health services planning councils whose responsibilities include the development of a comprehensive plan for delivery of HIV/AIDS preventive health services and establishment of funding priorities for the area.

NHF looks forward to working with you and the Subcommittee in achieving these objectives in H.R. 4470 as you write the Bill in final form.

NHF views H.R. 4080 as necessary to resolve the crises in access to health care, financing health care and in delivering health care created by the AIDS epidemic. NHF also sees specific provisions of the bill as offering benefits to the hemophilia community. Many hemophilia treatment center hospitals are in urban areas hardest hit by the AIDS epidemic. Those hospitals have suffered declining revenues due to lowered reimbursements from public and private third party payors. H.R. 4080 will provide hospitals with needed revenue for patient care and forestall potential



hospital limitations on such specialty services as comprehensive care for hemophilia. NHF is particularly supportive of the provision that allows Medicaid funds to pay for insurance coverage, as this will enable those persons with hemophilia who have become disabled to keep their private insurance.

We support the concepts embodied in both H.R. 4470 and H.R. 4080 and hope that there will be an opportunity to work with the Subcommittee in assuring that the needs of patients with hemophilia are fully addressed.

Mr. WAXMAN. Thank you. I want to thank the three of you. I am going to recognize each member for a round of questions and the Chair is going to use his discretion to say there will be only one round of questions. I want to advise members of that fact in advance.

Dr. McGrath, some have argued that one of the main reasons that people, especially poor people or people without health insurance, don't come in for counseling and testing is because they don't believe that such services can make any real difference to them, that testing is only a death sentence.

Do you believe that if early intervention treatment is made more widely available to these people without health insurance, especially the poor, that more people will volunteer for counseling and testing?

Mr. McGRATH. Yes, sir, we most certainly do.

Mr. WAXMAN. Anybody disagree with that? Certainly we want to provide funding for that health care treatment for these people.

Dr. Rickles, the number of hemophiliacs and their wives getting AIDS testing is reported to be very low. What are the major reasons that hemophiliacs have not come in for testing?

Mr. RICKLES. My personal opinion, Congressman Waxman, is that discrimination is the major concern of our patient population. I base that on my own experience with 128 individuals.

Mr. WAXMAN. They are fearful that they will be discriminated against by whom?

Mr. RICKLES. They are fearful of being discriminated against by individuals in their community, by employers, by health care insurers, by a variety of third parties.

Mr. WAXMAN. We are talking about the group, if you look at the three general groups, IV drug users, gay men, hemophiliacs that should be the least concerned about discrimination, but you think that they are sufficiently concerned about it to stay away.

I think the report—I think it is accurate to say that those that go in for testing is fairly low.

Mr. RICKLES. You are absolutely correct.

Mr. WAXMAN. Do you think if we had early intervention therapy available to these people that more would come in?

Mr. RICKLES. We do have some early intervention therapy, as you know, AZT has been proven to work. That has clearly increased the activity. Patients do come in more now for testing, but that alone will not secure their participation.

Mr. WAXMAN. Has there been a financial barrier to the——

Mr. RICKLES. A very clearcut financial barrier, yes, sir.

Mr. WAXMAN. Ms. Richardson, some people have suggested abbreviating or eliminating pretest counseling before AIDS testing. Do you support such a proposal and would it be good private or public medical practice?

Ms. RICHARDSON. No. We believe that the pretesting counseling is just as important as posttesting counseling.

Mr. WAXMAN. Dr. McGrath, is it necessary for the name of the patient to be recorded anywhere in order to do a partner-notification program?

Mr. McGRATH. It is not necessarily so, but our policy is that there are certainly instances where that might be necessary, and in those cases, with individual discretion where other means have been tried and failed, that that would be justifiable.

Mr. WAXMAN. Is it necessary for names to be gathered to do statistical or epidemiological work?

Mr. McGRATH. No, not names.

Mr. WAXMAN. The Congressional Budget Office has assumed that the additional cost of providing early intervention treatment will yield no reduction in costs of hospital care. Do you think this is a correct statement? Do you think that early intervention may reduce the overall costs of hospitalization?

Mr. McGRATH. I was impressed by the earlier physician's testimony from Maryland who seemed to have a great deal of experience and from the—some general knowledge of medical economics, that when you intervene early and you save the more costly—the higher-cost, devastating parts of the—it certainly seems logical and it is a premise of general health care.

Mr. WAXMAN. I suppose if we let people die without caring for them, the faster they die, the more money we would save, but all health care is to prolong life and to keep the health as good as possible for as long as possible and that does sometimes cost money.

Does the medical profession or the AMA subscribe to the notion that any test ought to be given to anybody without their informed consent?

Mr. McGRATH. Yes. There are instances where, without informed consent—and we spell those out in our policy—they have to do with prisoners—I would take that as to be mandatory testing—prisoners—

Mr. WAXMAN. No, don't take it as mandatory testing. Do you think that—would the AMA support the notion that it ought to be up to the doctor to decide whether an HIV test should be administered to a patient and not require that patient to give informed consent?

Mr. McGRATH. No, no, certainly, sir. Informed and knowing consent is our requirement.

Mr. WAXMAN. That is a basic ethical requirement, isn't it?

Mr. McGRATH. It is an ethical requirement.

Mr. WAXMAN. I want to recognize Dr. Rowland at this time and let him pursue his questioning, and give back the balance of my time.

Dr. Rowland.

Mr. ROWLAND. Thank you very much, and I apologize to my colleague, but I have to leave momentarily.

I just want to ask this question, because I am still concerned about the discrimination. We have heard that discrimination may not really play much of a part in this, that public good was something that we really need to be looking at and not giving much consideration to discrimination.

Let me ask you this question. Do you think that mandatory contact tracing would result in a decrease in testing, and if so, why?

Ms. RICHARDSON. I think mandatory contact tracing without discriminatory—antidiscriminatory protections would result in less people accessing testing. We know, as nurses, that a number of our patients have had problems with discrimination, both on their jobs and in their homes.

Mr. McGRATH. I believe, Dr. Rowland, we had something of a workshop in that this morning, sir, when we saw that from the people from several different States talking about several different populations were unable to agree. It is an excellent argument for why you have to have these programs crafted specifically for the State and for the locality. If public health officers in the State start to notice that part of the program like contact tracing is reducing their number of positives, then they have the opportunity to rethink the program.

Mr. RICKLES. I would agree with that statement.

Mr. ROWLAND. Thank you.

Thank you very much, Mr. Chairman.

Mr. WAXMAN. Mr. Dannemeyer.

Mr. DANNEMEYER. I would like to ask Mrs. Richardson—

Ms. RICHARDSON. Ms. Richardson.

Mr. DANNEMEYER. Excuse me, Ms. Richardson. Recommendation 27(e) of the American Medical Association provides as follows:

That the AMA strongly recommends the reportability of HIV seropositive patients to the departments of health of the 50 States for the purposes of contact tracing and partner notification.

My question to you, Ms. Richardson, is does the American Nurses Association endorse what I have just described to be the policy of the American Medical Association?

Ms. RICHARDSON. The American—

Mr. DANNEMEYER. That can be answered yes or no.

Ms. RICHARDSON. The American Nurses Association makes its own policies regarding AIDS. We are looking at the issue of contact tracing and mandatory reporting in 50 States. Right now, we support the recommendations of the territorial officers, State and territorial officers.

Mr. DANNEMEYER. As things stand today—

Ms. RICHARDSON. We do not endorse the AMA's recommendation.

Mr. DANNEMEYER. And also, Mr. Rickles, I would like to ask you, on behalf of the National Hemophilia Foundation, does that organization support the position of the American Medical Association Recommendation 27(e) that I have just read?

Mr. RICKLES. In view of our success rate with voluntary testing and voluntary contact tracing, we would not support that recommendation.

Mr. DANNEMEYER. I see. I would like to ask Dr. McGrath, the spokesperson here this morning on behalf of the AMA, in your opinion, would H.R. 4470 be improved if a provision consistent with AMA Recommendation 27(e) concerning confidential reporting were added to the bill?

Mr. McGRATH. Our belief is that you already have in your bill, sir, something quite consistent with Recommendation 27(e).



Mr. DANNEMEYER. No, I am saying—I am talking about Mr. Waxman's bill. H.R. 4470. My question to you is, would his bill, H.R. 4470, be improved if it included a recommendation consistent with the position of the American Medical Association, specifically Recommendation 27(e)?

Mr. McGRATH. It is my understanding, sir, that—he can certainly speak for himself—that the chairman's bill does include this recommendation.

Mr. DANNEMEYER. Mr. Waxman's bill does not include mandatory reportability and contact tracing that will be implemented at all—by all States in the Union. So my question to us is, would his bill be improved if it included the recommendation of the American Medical Association?

Mr. McGRATH. I believe it would, sir, if that is the case.

Mr. DANNEMEYER. Thank you.

Mr. WAXMAN. Would the gentleman yield?

Mr. DANNEMEYER. I will yield when my time is concluded.

Mr. WAXMAN. And I will look forward to that time.

Mr. DANNEMEYER. If you will give me some additional time, I will be happy to yield to you right now.

Mr. WAXMAN. Without objection, the gentleman will be given 30 additional seconds.

Would the gentleman yield on his 30 additional—

Mr. DANNEMEYER. I yield to the chairman.

Mr. WAXMAN. I want to refer to the bill. The bill provides that States provide assurances satisfactory to the Secretary that the State will require that any entity carrying out such testing confidentially report to the State Public Health officer information sufficient to perform statistical and epidemiological analysis of the incidents in the State of cases of such infection and, two, to perform statistical and epidemiological analysis of the demographic characteristics of the population, and the Secretary may not make a grant under section 2601 unless the State provides assurances satisfactory to the Secretary that the State will require that the State Public Health officer, to the extent appropriate in the determination of that officer, carry out a program of contact tracing with respect to cases of infection with the agent for Acquired Immune Deficiency Syndrome.

Mr. DANNEMEYER. Yes, but as you well know—

Mr. NIELSON. Mr. Chairman, I would like 10 of those 30-second intervals when my time comes.

Mr. DANNEMEYER. You know, there is a vast difference in the functioning of public health between the function of statistical and demographic data determination and identity link contact tracing, and that is all the difference between night and day between the provision that you have related in H.R. 4470 and my bill, H.R. 3102. It is clear to me that the recommendation of the American Medical Association is quite clear that the policy that should be implemented by States of the Union is, as it says, reportability of HIV seropositive patients to the departments of public health of the 50 States for the purposes of contact tracing and partner notification. That is the difference.

Dr. McGrath, I would like to continue, if I may. Would H.R. 4470 be improved if a provision were added that is consistent with the



AMA Recommendation 21(a) with respect to voluntary HIV testing in various clinical settings? Recommendation 21(a) reads as follows:

The AMA continue to strongly support the provision of voluntary HIV testing with informed consent for individuals who may have come into contact with the blood, semen or vaginal secretions of an infected person in a manner that has been shown to transmit HIV infection.

Among these persons might be, one, STD clinic patients; two, drug abuse clinic patients; three, those seeking family planning services; four, pregnant women whose sexual or drug history indicates the possibility of HIV infection and newborns of women who are or might be HIV-infected; five, persons with clinical signs and symptoms suggesting HIV infected; six, persons with tuberculosis; seven, persons who, during the period from 1978 to 1985, received units of blood from areas with high prevalence of HIV infection; and lastly, individuals who request testing.

Mr. McGRATH. Yes, sir, the bill would be improved. Further, might I say, sir—

Mr. DANNEMEYER. Yes.

Mr. McGRATH. We have probably 68 recommendations in here and we feel both bills would be improved by the incorporation of just about all of those.

Mr. DANNEMEYER. I thank the gentleman.

I have some other—Mr. Chairman, I have some other questions. I realize my time is expired. I would like to ask authority to submit these other questions to the representative from AMA and they can provide responses in due course, if I may do that.

Mr. WAXMAN. Without objection, we will ask that you respond in writing to questions that members may submit to you.

As I recognize Mr. Nielson, I want to say how pleased I am you endorse those provisions because they are already in our bill.

Mr. Nielson.

Mr. NIELSON. Thank you, Mr. Chairman.

I have a number of questions and I would like to submit some in writing as well that I won't have time for.

May I ask Ms. Richardson, you praised H.R. 4080 and H.R. 4470 and you said you endorsed them fully. You didn't mention H.R. 3102. Is there any redeeming virtue in H.R. 3102 or did you just happen to forget that one?

Ms. RICHARDSON. No, we have looked at H.R. 3102 and we have some of the same concerns that the AMA expresses in their testimony regarding that bill as well.

Mr. NIELSON. Do you agree with Dr. Rockett that there is some complimentary in H.R. 3102 that could be combined with a stronger total bill?

Ms. RICHARDSON. Not as wholeheartedly as Dr. Rockett.

Mr. NIELSON. I suspected that.

Let me ask another question to Dr. McGrath. You seem to like H.R. 4470 pretty well and I like parts of it myself. However, it does say something about States receiving grants have to provide a program of HIV contact tracing to the extent appropriate.

How would you define "extent appropriate"?

Mr. McGRATH. If you give me a second, sir, we will try to get the appropriate part.

We take that to mean to the extent appropriate by the local health authority.

Mr. NIELSON. Do you have any estimates how much it might cost States to provide Medicaid coverage for HIV-related health cases?

Mr. McGRATH. Did I not hear the chairman give a figure of something like \$2.8 billion or something this morning that came from the—

Mr. NIELSON. Would you like to—

Mr. McGRATH. That is over a 5-year period.

Mr. NIELSON. Would you like to also make your own estimate of that, as well?

Mr. McGRATH. I would be totally unqualified to do that, sir.

Mr. NIELSON. Would your organization try to come up with a figure like that?

Mr. McGRATH. Yes, sir, we will certainly address ourselves to that.

Mr. NIELSON. Let me ask another question in that regard. As I recall the catastrophic health care, one of the objections a lot of people—senior citizens had is that they had to care for people who had disabilities, and most of the AIDS victims qualified for disabilities under the Medicaid—under the Catastrophic Health Care bill and the senior citizens were not opposed to having help for those people, but they didn't think they, themselves, should have to bear that burden. That is one of the many objections to the Catastrophic Health Care bill.

Because that is the case, I think it is important that we know how much it is going to cost and who should bear it. My main concern is, if we treat it as a disability for Medicaid purposes, why do we not do that for other diseases, such as leukemia or other things which are life-threatening? Why don't we make those disabilities? I am not talking about discrimination. I am talking about comparability in this case.

Mr. McGRATH. We believe, sir, there is comparability. Right now, AIDS qualifies as a disability and we are only talking—the chairman is only talking in extending the period.

Mr. NIELSON. Does leukemia qualify as disability?

Mr. McGRATH. Certainly if one were to meet all the other qualifications for incorporation in the Medicaid program, it would.

Mr. NIELSON. Does a pacemaker in my heart qualify?

Mr. McGRATH. Yes, if the person were eligible for the Medicaid program, I believe that it would.

Mr. NIELSON. So you are not setting a new precedent, you don't believe?

Mr. McGRATH. No, we do not, sir.

Mr. NIELSON. Okay. You mentioned you didn't object—you liked some parts of H.R. 3102, but you objected to the fact that they should be called sexually transmitted diseases. Would you like to elaborate on that? What are the consequences—what are the potential dangers you see in requiring States to list it as a sexually transmitted disease?

Mr. McGRATH. The risk is not that States will do so, but that there be a Federal mandate that all States do so in some uniform sort of way, and the risk would be, as your own questions brought out this morning, sir, the differences there are between the States, such as Arkansas and what we heard about in New York City for the program to be effective. We do not know what the sexual transmitted diseases and the implication of lumping that would mean in each and every jurisdiction.

It could be counterproductive. It certainly could.

Mr. NIELSON. One question—

Mr. McGRATH. We want local jurisdiction, sir.

Mr. NIELSON. Our time is gone and we do have to go for a vote, but I do have to ask Dr. Rickles two questions.

Hemophilia right now—are hemophiliacs eligible for Medicaid presently, under present law?

Mr. RICKLES. If they meet the other criteria.

Mr. NIELSON. You suggested we need to add specific protections for hemophiliacs into the bill, H.R. 4470. Do you have legislation or suggested language so we could do that?

Mr. RICKLES. Yes.

Mr. NIELSON. Would you like to supply that to all members of the subcommittee?

Ms. ROCKETT. We would be pleased.

Mr. NIELSON. I appreciate that.

Would expanding Medicaid coverage to include HIV-positive capture many individuals of hemophilia as well?

Mr. RICKLES. I am sorry, could you repeat that, sir?

Mr. NIELSON. Would expanding the Medicaid coverage to include HIV-positive patients capture many of the hemophiliacs which are not now eligible?

Mr. RICKLES. It would capture a significant percentage. I can't give you specific numbers.

Mr. NIELSON. Is the HIV virus continuing to spread among hemophiliacs?

Mr. RICKLES. They no longer are exposed to the virus through factor 8 or factor 9 concentrates which are now HIV-free, but heterosexual spread does continue to occur.

Mr. NIELSON. I had other questions. I will submit them in writing.

Thank you, Mr. Chairman.

Mr. WAXMAN. Thank you, Mr. Nielson.

Thank you, all, for your testimony today. We look forward to working with you on this legislation.

That concludes the hearing for today and we stand adjourned.

[Whereupon, at 1:21 p.m., the hearing was adjourned.]

[The following statement was submitted:]

#### STATEMENT OF THE ASSOCIATION OF AMERICAN PHYSICIANS AND SURGEONS

Although the stated purpose of this legislation is to prevent AIDS, its actual effect will be to prevent the control of the human immunodeficiency virus [HIV] by impeding diagnosis and blocking implementation of proved public health measures.

Of greatest concern is section 2601, the requirement that testing be done only with written, informed consent, and after extensive counseling.

Such a requirement would mandate ignorance in precisely those situations that most urgently call for a timely and accurate diagnosis: (1) a patient who is unconscious or mentally incompetent; and (2) exposure of another person, such as a sexual partner or health care worker. The irrationality of this requirement is made readily apparent in later portions of this same law. Section 2643 establishes civil monetary penalties for knowing or negligent violation of section 2641, which requires notification of an emergency response employee in the event that an infectious disease is diagnosed. Yet, according to section 2642, medical facilities shall not be authorized or required to test for any infectious disease. All emergency workers know that they might have been exposed to an infectious disease. When counseled after a needle-stick injury, what they most want to know whether they actually have been exposed to a particular disease.



Failure to test patients whose blood might have infected another person is most commonly justified by asserting that (1) the risk of transmission is "low" and (2) there is "nothing that can be done about it anyway." Both of these assertions are false.

What is the risk of infection resulting from an occupational exposure? Because of the scarcity of data (due to failure to test an adequate number of persons), estimates are subject to considerable uncertainty. But it is clear that the risk varies greatly, depending on the results of the source patient's HIV test.

The risk of acquiring HIV after a single stick with an HIV-contaminated needle is about 1 in 250.

If the source patient's blood test is negative, but the patient is in a very high risk group (say one with a 50 percent prevalence of infection—e.g. the gay male population of many communities), the risk of acquiring HIV after a needlestick is about 1 in 10,000.

If the source patient's blood test is negative and the patient is a randomly selected member of the US population, the risk of acquiring HIV after a needlestick is less than 1 in a million.

The difference between a 1 in 250 risk and a 1 in 10,000 or 1 in 1,000,000 risk might be highly significant to a worker who is faced with deciding what to do after an exposure. The alternatives include: (1) doing nothing except possibly having his or her own blood test checked; (2) abstaining from sexual activity for a prolonged period, pending test results; (3) avoiding pregnancy; (4) avoiding breastfeeding; (5) immediately starting prophylactic treatment with zidovudine, an expensive, toxic drug that might decrease the risk of infection (and might cause later cancer or birth defects); (6) using condoms for a prolonged period. (The last, while often touted as the best solution, is morally objectionable to many persons and has an unknown failure rate, perhaps 17 percent according to one study.)

To keep the numerical risks in perspective, it is helpful to remember that the Clean Air Bill proposes to shut down any industrial facility that subjects its most exposed worker to a greater than 1 in 10,000 hypothetical risk of future cancer.

Presumably, the rationale for the written consent requirement is to protect patients against a variety of supposed dire consequences of the test itself. In actuality, the consent form is itself useless for this purpose unless it prevents testing. (Consent forms are generally intended to protect physicians and hospitals against liability.) Protection against harm due to breach of confidentiality needs to be assured by methods other than enforcement of ignorance. The protection offered by ignorance is only temporary, as the disease will almost certainly manifest itself in due course. And the tradeoff may be highly disadvantageous to the patient: an illusory protection bought with a delay in diagnosis and the consequent omission of treatment that could retard the development of frank AIDS.

Section 2603 establishes elaborate, expensive requirements for counseling that will discourage testing or make it impossible in certain instances (e.g. an unconscious or mentally incompetent patient cannot be counseled). Yet when counseling is done, the single most important piece of information is the results of the HIV test. And the most important action is the notification of the seropositive patient's contacts, in a manner that preserves confidentiality.

Neglect of contact tracing can have startling consequences. If each infected person transmits the infection to one other person each year, a single case can lead to 1,024 cases in ten years. (The first year, one case becomes two; the second year, two cases become four; the third year, there are eight; and so on.)

Early results of partner notification programs for HIV infection are promising. The Colorado Department of Health estimated that each \$1 invested in partner notification would save \$5 in direct medical care costs alone (Consultant, June, 1989, pp. 43-46). A program in South Carolina found that contact tracing was an efficient use of HIV testing, with 13 percent of contacts testing positive. This program seemed to bring about significant behavioral changes (JAMA, June 24, 1988, pp. 3563-3610). Partner notification programs have warned many persons, especially women, who otherwise would have been unaware that they were at high risk of infection. The principal argument advanced against such programs is that they cannot locate all contacts. Such an argument could, of course, be used to deny any benefit to any person if it could not be guaranteed to all. The fear of breaches of confidentiality by public health officers is so far a hypothetical one; in any case, blinding and gagging the public health officer is not the appropriate response.

Although this legislation mentions contact tracing, to the undefined "extent appropriate in the determination of the [State public health] officer," it does not require confidential reporting of information sufficient to locate the infected individual so that the contact tracing can be done.



Section 2608(b) prohibits an applicant for a grant from requiring patients to undergo testing as a condition for receiving health services "unless such testing is medically indicated in the provision of the health services sought by the individual."

This provision is open to interpretation that should be chilling to any person or institution offering health services. Like diabetes or coronary artery disease, infection with HIV is a pertinent part of the medical history regardless of the reason for seeking medical treatment in any particular instance. If treatment has an adverse outcome that might have been averted by prior knowledge of these conditions, the physician is accountable for the tort of failure to diagnose. Further, an accidental exposure to the patient's blood has profound implications for the affected worker. Besides the risk of contracting a fatal disease, there is the risk of infecting others, even before the worker's own blood test becomes positive. To minimize that risk might require radical changes in lifestyle. Demanding that any worker face this prospect without allowing access to the best available information is an unconscionable violation of the worker's civil liberties. Subjecting another human being to risk of lethal harm without his or her knowledge and consent is not acceptable behavior—not even for a person who is himself a victim—and should not be sanctioned by law.

Because we do not yet know the extent of the epidemic of HIV disease, the potential cost of this section is incalculable. And the cost mounts with each delay in the decision to treat HIV disease like an infectious disease.

At the present time, cutbacks in other areas of the Medicare and Medicaid programs are driving hospitals into bankruptcy. Blue Cross/Blue Shield of Kentucky, the federal Medicare carrier, recently cut coverage for surgeons' fees by an average of 30 to 40 percent. An open-ended expansion of benefits to victims of one particular disease cannot be justified at a time when patients with diabetes, heart disease, and cancer are facing dramatic cuts. Medicare patients may pay with their lives for zidovudine and other treatments for AIDS victims.

The Association of American Physicians and Surgeons supports legislation (such as H.R. 3102) that calls for uniform treatment of all communicable and/or sexually transmitted diseases, including the implementation of standard, proven public health measures.

The Association is opposed to H.R. 4470 because it creates additional costly impediments to the diagnosis and containment of HIV infection. Its cost should be measured not only in dollars but in lives and in the loss of civil liberties by persons exposed to the virus.

The Association believes that all persons are entitled to equal protection under the law. Emergency response and other health care personnel deserve the same consideration as workers in other industries. H.R. 4470 denies them this right. Other contacts of infected persons, such as inmates in the same prison, rape or assault victims, and sexual contacts, deserve the same protection against HIV disease that they automatically receive from the public health department if the threat is tuberculosis, syphilis, measles, or other contagious disease. H.R. 4470 would further codify the present discriminatory treatment of persons who are unknowingly or unwillingly exposed to HIV disease.

It is time to set aside political considerations that have already caused untold suffering and preventable loss of life.







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